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ABSTRACT

Twenty-five papers are presented from a May, 1983 interdisciplinary conference on the visually impaired child. The following papers are presented: "From Seeds to Fruit" (E. Scott); "Sources of Self-Esteem and the Adjusting Process" (D. Tuttle); "Electronic Travel Aids for Children: Advantages and Disadvantages" (J. Wadsworth); "What Happens When My Computer Aid Breaks?" (H. Riddel); "Visually Impaired Children and Their Siblings" (W. Doust); "An Approach to the Audiologic Assessment of Multi-Handicapped Deaf-Blind Children" (R. Folsom and J. Moore); "What Is Mobility? Independence, Confidence, Self-Esteem" (R. Emery); "Toward an Understanding of Language Symptomatology of Visually-Impaired Children" (B. Prizant); "Adapting the Environment for the Visually Impaired Student: Practical Methods and Materials to Enhance the Use of Low Vision" (L. Roessing); "Neurovisual Adaptations to Subnormal Vision in Children" (C. Hoyt); "The Function of a Low Vision Clinic and the Use of Aids" (A. Pratt); "Recent Advances in Ophthalmic Genetics" (J. Carruthers); "Blindness in Children: Epidemiology and Prevention" (G. Robinson); "Filters for Protection, Comfort, Therapeusis and Vision Enhancement" (A. Cullen); "Diagnostic Clues in the Physical Appearance of the Visually Impaired Child" (J. Jan); "Various Topics in Pediatric Ophthalmology: Questions and Answers: (A. McCormick and C. Hoyt); "Conceptualizing the Gifted Blind Child" (E. Chorniak); "The Effect of Motor Handicap on the Development of Visually Impaired Children" (A. Sykanda); "Sexual Insight: Exploring Sexual Issues with Visually Impaired and Multihandicapped Persons (G. Szasz); "Reconceptualizing the Development of Young Blind Children" (I. Davidson and J. Simmons); "A Comprehensive School Based Physical Education Programme for the Visually Impaired Child" (J. Maitland); "Career Awareness and Preparation: A Group Effort" (J. McConnell); "I Can Do It with Exposure, Experience, Expectation and Enjoyment" (L. Harrell); "Personal Imagery and the Visually Handicapped" (J. Macdonald); and "Living Skills: The Dual Role of the Parent and the Professional" (D. Brent). (CL)

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INSIGHT IN SIGHT

Fifth Canadian Interdisciplinary Conference on the Visually Impaired Child

VANCOUVER, BRITISH COLUMBIA, CANADA

OCTOBER 18-20 1984

EC180533

I N S I G H T I N S I G H T

PROCEEDINGS OF THE FIFTH CANADIAN INTERDISCIPLINARY CONFERENCE ON THE VISUALLY IMPAIRED CHILD.

VANCOUVER, BRITISH COLUMBIA

OCTOBER 18 - 20, 1984

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EC180 533

FORWARD

In May, 1983, a group of people from the Visually Impaired Program at British Columbia's Children's Hospital and the Canadian National Institute for the Blind, British Columbia - Yukon Division first met to begin planning the Fifth Canadian Interdisciplinary Conference on the Visually Impaired Child. Represented in the initial group were professionals from a wide variety of disciplines, and in subsequent early meetings our "core" planning committee expanded to include representatives from the Association for Visually Impaired Students, a parent organization.

The diversity of backgrounds, interests, and viewpoints represented in the planning committee is directly reflected in the diversity of topics covered during the conference. This resulted in a truly interdisciplinary exchange, which made this conference so very exciting. It also provided our speakers with a challenge in preparing talks that would be interesting and informative to such a diverse audience. Judging from the feed-back from conference participants, the speakers rose to this challenge admirably, and we are very pleased to be able to offer papers of such a high calibre in these proceedings.

We would like to take this opportunity to thank all the people and organizations that donated time, ideas, and funds towards the conference. Without them it could not have been the tremendous success that it was. In particular, we would like to thank the members of the conference planning committee, who selflessly and enthusiastically donated hours and hours of their time. It was a privilege to work with such a tremendous group of people.

In our experience an interdisciplinary approach has illustrated time and again the adage "The whole is greater than the sum of its parts." In this case we feel that the insight gained by sharing our knowledge in interchanges such as this conference far exceeds any understanding we gain by examining the visually impaired child from within the confining viewpoint of our own profession or experience. It is our hope that the sharing of information and ideas that occurred at this conference will continue in the future. Exchanges such as this conference cannot help but to have a positive impact on the lives of the visually impaired children in our care.

Susan Blockberger,
Barbara Buchanan,

Conference Co-Chairpersons.

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FROM SEEDS TO FRUIT

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I am delighted to see so many old friends and so many new faces -- all of you interested in visually impaired children. It is wonderful! A far cry from the early days! Sylvia Keet has mentioned the trivet with the seeds which was presented to me at one of our first conferences with a little note saying that I had helped plant the seeds of work with blind children and hoping that those seeds would flower and bear fruit -- hence the title of my talk this morning. I have been asked to tell you about some of those early days and some of the people who were involved in the seed planting. As history goes it is very short, less than forty years, based primarily in British Columbia and of necessity very personal.

It begins in 1945 when I joined the staff of the Canadian National Institute for the Blind as prevention of blindness worker. The CNIB was founded in 1918 by four blinded soldiers as an agency to provide rehabilitation and other services to the blind adults of Canada. At the time they applied for their national charter there were already in existence schools for the blind in Halifax, Montreal, Brantford and Vancouver. The schools, fearful of interference, lobbied successfully and it was agreed that the CNIB would not become involved with the education of blind children. Thus the CNIB served blind adults, the schools taught children from 5 to 20 and nobody paid any attention to the preschool children for a long, long time. By the 1940's the enrolment at the schools had dropped to an all-time low, as compulsory use of silver nitrate drops at birth, vaccination and innoculation had prevented the infectious diseases previously responsible for much of the blindness in previous times. In the B.C. School for the Blind there were only 15 students in 1946 and half of them were what were called sight-savers.

So there was the setting when I joined the CNIB staff, having taught grade 1 for 8 years and being enrolled as a part time student in the School of Social Work at UBC. The only social worker in the entire agency and a sighted one at that, all the rest of the service staff being blind. My caseload was entirely composed of adults.

In 1947, there occurred a series of events which resulted in my life long involvement with visually impaired children and their famiies. First a distraught young woman placed a parcel on my desk and ran out. The parcel moved and in it I found a very small, young baby. By the time I had gathered my wits the mother was a city block away, but I chased her and brought her back to the office. She said the baby was blind and she did not want it and she wanted to give it away. I took her over to the Children's Aid Society but she abandoned the baby downtown that night. In September, a few weeks later, a woman phoned to ask if I would accompany her and her blind six year old son out to register at the School for the Blind. The boy was a big sturdy child, but he had never walked alone outdoors without holding his mother's hand. His conversation was peculiar, mainly parroting and he seemed a very weird child to me. I have never forgotten the shock of my first visit to the school 37 years ago. We were taken to the primary room grades 1 to 3, where seven little blind children crouched around a table with their fists pressed tightly to their eyes. They sat motionless while the teacher talked to us for at least half an hour. I could not get over the contrast between them and my former boistrous, energetic grade one students. I could not accept that blind children had to be like that and promised myself to try to do something to change it. What, I hadn't a clue.

A few days after my visit to the school I received a phone call from Dr. Howard Mallek, a young ophthalmologist, who said that he and Dr. Peter Spohn, a paediatrician, had several blind premature babies in the nursery at St. Paul's Hospital and would like me to help their parents cope with them. I said I did not know anything about blind babies but would do what I could to help. Very soon we heard that there were several older blind babies in Victoria. It soon became apparent that as the hospitals modernized their nurseries with the new incubators, blind babies began to appear. First in one Victoria hospital, then the other, then St. Paul's, followed by the Vancouver General Hospital, St. Mary's and the Royal Columbian in New Westminster, and on across the province. The same thing was happening all over North America. From 1946 to 1954 more and more premature babies became blind as the doctors searched frantically for the cause. The number rose to 700 a year in the U.S.A. at the peak. In B.C. we had over 100 cases in all. I remember Dr. Mallek saying if he had a premature baby he would keep it at home in an apple box on the oven door.

In 1954 Dr. Phillip Ashton, doing research on high altitude flying in England found that he could induce the same eye changes in newborn kittens by exposing them to excess oxygen.

Soon after that all premature nurseries limited the amount of oxygen and the number of babies blinded by this eye condition (named retrolental fibroplasia) fell off dramatically. Incidentally I recently read an article from the New York Times that the incidence of retrolental fibroplasia in the U.S.A. is again on the increase, raising doubts that oxygen is the sole cause. They are now saving much smaller babies. Our early little ones were in the 2 to 3 and a half pound range whereas they now are in the 1 to 2 pound range.

It was a very exciting time. I kept records of all the B.C. babies, birth date, birth weight, gestation period, how long in the incubator, how long on oxygen, etc. These records were very useful in our subsequent research on visually impaired children.

Not knowing much about blind babies I frantically searched the literature but there was literally nothing beyond a few philosophical books and a couple of pamphlets dealing with toilet training and feeding. Visiting in the parent's homes I admitted I knew very little but wanted to help and if they were willing, we could learn together. They were desperate enough to agree. Since I also had responsibilities to blind adults, strictly to save time I asked the mothers to meet me in small groups, usually in someone's home. That group of preschool parents started in 1948 and continued with changing personnel until I retired in 1978 -- 30 years exactly.

The Director for Western Canada of the CNIB at that time was Capt. M.C. Robinson, a man far ahead of his time. At an AAWB convention he met a Dr. Berthold Lowenfeld, a psychologist, recently come to the U.S.A. from Vienna who was a specialist in blind children. Dr. Lowenfeld had just taken over as Superintendent of the California School for the Blind. The Delta Gamma Sorority which served as volunteers for the CNIB told us that their California chapter was sponsoring a residential nursery for blind children in Los Angeles so I was sent down to live there for a month. I also met and spent time with two women who Dr. Lowenfeld had just hired to provide counselling service to parents of blind babies in their homes, working out from his school. From my own observations and with Dr. Lowenfeld's encouragement I decided we were on the right track in working through the parents rather than directly with the children. Elsewhere residential nurseries were springing up, modelled on the Sunshine Homes of Britain which had been established for some years and were based on the theory that only experts could properly train blind children.

The first questionnaire I sent out to parents was in 1950 - there were only 18 -- and we asked what things concerned them most about having a visually impaired child. They were: doubt about their own ability to cope, educational provisions, and the child's acceptance by the community. Those concerns have changed little in 34 years. The parents were involved in the development of the program from the very beginning and that is why later on we were able to have access to some 1200 children from our research work. They were always an integral part of it.

The approach used in working with the parents was based on that early questionnaire and consisted of emotional support, information, and encouragement to become involved in the ongoing program.

It soon became apparent that our work was most productive if we reached families as early as possible, before their attitudes became firmly fixed toward the child and his visual impairment. In order to achieve these early referrals, letters were sent out on the advice of the Advisory Committee to all ophthalmologists and paediatricians and Public Health Nurses in the province telling them that early referrals would enable their patients to receive maximum help. The response was good and the referral level was well over 90%. Similar letters were sent every four or five years.

From parents' reports it soon became evident that the parents were not satisfied with the level of care they were receiving from their family doctors. Whenever it was possible we suggested they ask to have the child referred to Dr. Spohn and his new partner Dr. Geoff Robinson. Dr. Spohn died and Dr. Robinson was appointed as head of Childrens Outpatients Department at Vancouver General Hospital in 1954. He continued to see the visually impaired children there and to get them seen by a variety of specialists if they needed it. This was before B.C. Medical and the Outpatients was run on a means test basis, and few of the families qualified. Our good friend Dr. Robinson was a master at cutting or stretching red tape and somehow he got them all seen.

I will always remember one family. The mother of a blind baby phoned the B.C. Tel operator and said that she had to take her blind baby by bus to an ophthalmologist, a heart specialist, a bone specialist, a neurologist with offices all over town, and then she said, "Doesn't any one care about me and my baby?" The operator told her to phone CNIB and that is how I met her. She was a young Danish woman who had recently come to Canada with her husband and did not know anyone. I referred her to Dr. Robinson and he arranged for the child to be seen

by the specialists at Outpatients so she just had to come to one place. And then he explained the whole situation to her and continued to see the baby regularly.

Dr. Robinson did a great deal to make the other doctors aware of visually impaired children. He shared his enthusiasm with his co-workers and the residents and interns and medical students. Every few years he arranged for a program on visually impaired children at paediatric and family practice ward rounds. He was able to scrounge up funds for several summer projects on blindness and also for the production of our film "Shelley".

Dr. Robinson was also the founder and first director of the Children's Hospital Diagnostic Clinic in 1970, where the first multidisciplinary clinic for visually impaired children was developed. He was also responsible for the recruiting of Dr. Jim Jan, my good friend and the Program Chairman of this conference. They were also both involved in the very first conference we had on visually impaired children right here in Vancouver in 1974.

The ophthalmologists were also most cooperative. When I first came to CNIB I worked twice a week for three years at the Outpatients Eye Clinic at the Vancouver General Hospital, which proved most useful in learning about eyes, but even more useful in getting to know the senior eye men, and also all the residents as they came along. It provided an opportunity to convince them of the need for early referrals of visually impaired infants. Dr. Eliot, the Head of Ophthalmology was most helpful and arranged for me and usually a panel of parents to speak to all the ophthalmologists every year or so. As a result we had nice early referrals. One eye specialist used to phone up and say "I have Mr. and Mrs. Jones in the office. They have a blind baby and I am sending them up. Let me know if they don't show up." He had them scared not to come.

Most of them were not good at talking to parents and were glad to have someone to refer parents to. Dr. John Pratt Johnson and Dr. Andrew McCormick were always good with parents, made nice positive referrals and for many years were and still are very much involved with visually impaired children.

Before 1946 no CNIB staff member had ever been in the B.C. School for the Blind, as it was then known. Because I had been a teacher I was accepted, perhaps a bit reluctantly, and there ensued many years of collaberation with the school. I am sure that many times they wished I would get lost.

One of the major concerns of the parents was that Jericho Hill School, as it became known, was a residential school, and they wanted their children to live at home. We arranged to hold our parents meetings at the school sometimes and for the staff to talk to the parents. The parents and the CNIB helped the school campaign for a new modern building on the basis of the statistical projections about future needs. A nice modern building was built by the Provincial Government. Then the parents formed a PTA and raised money for two buses, presented them to the Easter Seal Society to provide transportation for blind children, talked the Provincial Government into granting them a transportation allowance for each child not residing at the school, and all children within 20 or so miles were able to become day students. Now that is parent power!

At its peak the population of the school was around 150 students. The parents began to want their children to go out to regular high school or late public school after they had learned their special skills at Jericho Hill School and Gerry Dirk was the first student enrolled at Kitsilano School, Grade 11 in the early 1950's. He was totally blind, a good student, a great piano player and had an outgoing personality. With the exception of having his books transcribed into braille he had no support services, but nevertheless did well. Gradually more and more senior students started to leave Jericho School for the public schools and with the decline in the number of retrolental fibroplasia cases the enrolment at the school began to decline. This so concerned the administration of Jericho Hill School that the superintendent and the principal paid a call on my boss, Captain Robinson and demanded that he make that woman stop encouraging parents to take their children out of Jericho. Captain Robinson agreed that I would not disucss school leaving with the parents until after they had discussed it with the school staff. A very diplomatic solution, but it did little to stem the tide.

Then there were the two totally blind, but very bright students who were enrolled in sighted schools in 1954 and 1955 in grade one. Those parents learned braille and we had volunteers transcribe the readers, but the texts were so full of errors that those two children both believed that adults were incapable of writing correct braille. There were no support services and that volunteer transcribing was the beginning of the full range of support services now available to the visually impaired children of this province. We had no resources, we just had to improvise.

In 1949 the first B.C. blind child, Judy Ewert, was enrolled in a sighted kindergarten. There were seven turndowns before one brave teacher accepted her in a private nursery school.

That was when there were no kindergartens in the public schools. From that year all visually impaired children were enrolled in a sighted preschool group whenever one was available in their neighbourhood, and any support services were supplied by CNIB. When kindergartens were opened in the public schools they refused to admit any visually impaired children for several years because of insurance liability. We sneaked in a few and their reluctance gradually disappeared.

Because the Superintendent at Jericho Hill School was inclined to admit any visually impaired five year old, however immature, and I was not, the parents were caught in the middle. The problem was avoided by having all applicants screened before admission by the Child Guidance Clinic and Metropolitan Health staffs. This function was taken over in 1970 by the Children's Hospital Diagnostic Clinic. All visually impaired children are screened in their preschool years and still are in the program for visually impaired children now operating out of the new Children's Hospital.

Since all the visually impaired children went to Jericho Hill School in the early days we tried to get them involved with sighted children socially through community groups. Many a time I tried to convince a reluctant child, reluctant parents and a reluctant group leader that integration into the group would be a positive experience for everybody. I would stop and wonder why I was knocking myself out when no one else was very interested. But it did work out. Merv Oveson, now a senior Parks Board and Recreation official, said he was tempted to jump off the dock when confronted by his first blind camper. He became one of the most keen proponents of integration of the handicapped into public recreation programs.

In 1958 CNIB organized a workshop on the social and recreational needs of visually impaired children for all parents and the heads of all organizations providing leisure time activities in the city. The group leaders did not know of the need and the parents did not know of the resources. It was a great success and helped facilitate the integration of visually impaired children into all sorts of community groups. At the present time there is a different need ie., to provide opportunities for the visually impaired children to meet other visually impaired children and to learn some of the special techniques and skills of being blind.

Now let me mention a few of the flowers which have grown from some of those early seeds. While in the beginning only a rare few doctors were interested, nowadays as the numbers of acutely ill children have decreased due to the new drugs and

the drop in the birth rate, more and more physicians of all kinds are becoming interested in chronic conditions including visual impairment. There are paediatricians, ophthalmologists, neurologists, geneticists and other specialists interested and very involved in many Canadian centres. There are multidisciplinary clinics geared to visually impaired children in a number of Canadian cities, within reach of most families. Since many of the children are multihandicapped this is most desirable.

Referrals are earlier and supportive services are available to parents in most parts of the country when they need it most in the early months.

Across Canada visually impaired children are being integrated into public school classes. Transcribing services, loaned special equipment and support services from itinerant teachers are now available in most areas. There are regional differences in the programs but this is desirable, as is the fact that residential schooling is still available at Halifax and Brantford if it is in the best interest of a particular child, particularly the multihandicapped.

The CNIB is no longer the only source of help. It is also available from groups like Infant Development Programs. It does however have a most important role to fill in the future and should continue to provide the essential functions of registration and referral, coordinating services so no child falls between two agencies, seeing gaps in services and seeing that they are filled. The CNIB should continue to function in the service to visually impaired children.

You who are sitting here this morning are the real flowers which have grown from our seeds --- each one of you interested and concerned with meeting the varied needs of visually impaired children and their parents --- from many disciplines, working together sharing the successes and failures. This is far differ[illegible] from the United States where educators have been the main g[illegible] to become involved in services to visually impaired c[illegible]ren. For me you make a lovely flower garden with many [illegible]erent colors and shapes of flowers. I hope you keep on bl[illegible]ng in increasing numbers.

While I co[illegible]er you who are providing a multitude of services to visuall[illegible]paired children and their families to be the flowers which have grown from our early seeds, I must not forget to mention the next step in our cycle and that is the fruit of our labors, ie., those good things which are now happening to benefit the community, to repay it. First, did you know that there is more real top-notch research on

visually impaired children being done right here in Vancouver than anywhere else in the world? Dr. Jim Jan and Dr. Geoff Robinson and their cohorts are discovering and publishing all sorts of fascinating new information which is attracting world-wide attention and will enable physicians everywhere to provide better health care for visually impaired children.

The parents of many visually impaired children are repaying their communities in different ways for help they have received. Some have trained for service professions and are now active as social workers, special education teachers, school librarians, nurses, child care workers, etc. They are active on boards and committees to improve and develop needed services. Others are making their contribution in very personal ways. One mother of a blind autistic daughter has been instrumental in the development of a group home for young adult autistic persons, and many group homes across the country have been helped into existence by parents of visually impaired young adults. Others do it in a different way. I remember being called to Vancouver General Hospital in 1968 where they had a two year old Indian child who had both eyes enucleated because of retinoblastoma. The Children's Aid had been searching unsuccessfully for six months for a foster home as the child's parents had abandoned her. I asked some mothers at a Friday meeting to enquire among their neighbours if anyone knew a potential foster home for this youngster. First thing Monday morning one of the mothers, who had a 12 year old blind daughter phoned to say she and her husband had talked it over and they thought it would be a shame to waste all the knowledge and skills they had learned so painfully in raising their own child, and had decided they would like to take the two year old. That child has given them tremendous satisfaction and is today an excellent student in high school and winning medals in world class swimming. That's nice.

But the sweetest fruit to me is what some of the visually impaired children I used to know as infants are now doing. Remember Gerry Dirk, the first blind student to go out to regular high school? He has left a successful career as a professor of political science at an Ontario university to take on the job of Executive Director of the Ontario Division of CNIB, the second highest post in the agency. Others have made successful careers as professors, teachers, computer programmers, electronic engineers, income tax advisers, good tax paying citizens with families of their own. Four or five of the early babies now sit as members of the CNIB Board of Directors, others are active in other agencies and civic activities.

Every so often I get a phone call or a letter saying "Remember me? I thought you would like to know about my new job, or wedding or a recent trip to Africa."

I feel very proud and hope you feel proud too. We have come a long way.

SOURCES OF SELF-ESTEEM AND THE ADJUSTING PROCESS

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INTRODUCTION:

Increased attention has recently been directed toward meeting the effective needs of visually impaired children and youth. My perspective on counselling toward effective growth is influenced by two factors: My Christian beliefs and my professional training in Special Education. The focus of my interest is targeted on the counselling needs of handicapped school-age children and their parents.

One of the underlying premises of this presentation is that there is no unique psychology of disabled persons (Lowenfeld, 1981; Wright, 1960), but rather, that the general psychological principles for the understanding of all human behavior are sufficient to explain the behavioral impact of a disability (Kirtley, 1975). With this basic understanding, there is a need to examine the relationship between the teacher-counsellor and the visually impaired student's family.

Another basic premise of this paper is that visually impaired persons are not necessarily abnormal or maladaptive in need of long-term, in-depth therapeutic counselling. Disabled persons are, in the main, normal people who are responding to life's demands with the added stress of a physical impairment. In this respect, I tend to agree with Rogers (1951 - 1961) and Maslow (1970) that normal people, through counselling, can become stronger, healthier, fuller functioning, self-actualized individuals.

Sources of Self-Esteem

To understand the visually impaired person's sources of self-esteem, one must first examine the impact of a visual disorder on the emerging self. A few general principles related to the development of self, self-concept, and self-esteem will be reviewed. A discussion of the sources of self-esteem and the impact of a handicap follows. Finally, this section concludes with an overview of some of the problems that visually impaired persons must resolve.

The emerging self, self-concept, and self-esteem:

Despite the legislative and advocacy efforts of the past decade, individuals with a visual impairment are not yet fully assimilated into society. According to Maslow's hierarchy of needs, if love and belonging needs have not been met, then self-esteem needs are not yet salient. Only when self-esteem needs are met do self-actualization needs become salient. The following observations about self, self-concept, and self-esteem have been synthesized from many writers: Coopersmith (1967), Dobson (1974), Fromm (1947), Gergen (1971), Hamechek (1971), Horney (1945), LaBenne and Greene (1969), Maslow (1954, 1970), Mead (1934), Robers (1951), and Stringer (1971).

People strive for personal adequacy, a universal basic need, by engaging in self-enchancement activities. A person's ability to cope successfully with life's demands depends on his personal adequacy. Personal worth is not optional, it is mandatory to the emerging self-concept.

People behave in ways that are conguent with their self-concept. A person's self-concept and personality structure is developed early in life and remains relatively constant throughout life. This self-abstraction is formed in social interactions, personal reactions to himself, mastery in solving developmental tasks, and competence in dealing with life's demands.

While the self strives for unity, consistency and equilibrium, it can also be multi-dimensional. Until threatened with exposure, a person's self-concept can tolerate a certain amount of inconsistencies. The self-concept is reinforced or modified by every life experience.

Self-esteem is the affective component of self-concept. A person's self-esteem not only determines the interpretations given events in his social and physical environment, but is, in turn, affected by those interpretations. Healthy self-esteem results from valuing self and being valued by others.

A person's attitudes toward himself determines his attitude toward others. An individual must experience a measure of self-love and self-acceptance before he can love and accept another. Acceptance by others is predicated on a person's self-acceptance and his acceptance of others. Therefore, self-esteem, self-acceptance, acceptance of and by others are inextricably intertwined.

Self-esteem, rather than being fixed, is responsive to changes in time, space, situational demands, and apparent discrepancies between the real self and the ideal self. Threats to the self-concept may alter an indivual's level of self-esteem. "Satisfaction of the self-esteem need leads to being useful and necessary in the world. But thwarting of these needs produces feelings of inferiority, of weakness, of helplessness" (Maslow, 1970, p. 45).

Sources of Self-esteem and the Impact of a Visual Impairment:

Self-esteem is influenced by two sources: reflections from others and judgements of one's competence. Younger, more immature, or more dependent individuals tend to rely on reflections for their self-esteem. As the locus of control and the locus of evaluation become more internalized, the individual is freer to become uniquely and fully himself.

Early in the developmental process, reflections from others play an important role in shaping one's self-concept and self-esteem. A person tends to incorporate the signals received from his significant others into his own self-concept. When a person is valued and accepted by others, he will be more inclined to value and accept himself. A person receives multiple reflections from multiple significant others at many different times and places in his life.

Many of these reflections are discrepant with each other and many may be discrepant with his own self-concept. In fact, handicapped individuals experience a wider range of inconsistent, predominantly negative reflections, which results in lower self-esteem. When discrepancies are persistant and strong, the self must resolve these discrepancies to maintain its unity, consistency and equilibrium.

Another major source of self-esteem is the continuous internal process of making judgments about one's own competence (Tuttle, 1984). Out of a visually impaired person's self-concept or perceptions of his own personal attributes emerge his aspirations and goals in life. His aspirations determine the tasks and activities he chooses to accomplish. His performance of these tasks and activities is evaluated against a standard of his own choosing. Judgments about the extent of success in accomplishing his goals are weighted by the salience and significance of the value of that task or activity. Weighted judgments of success or failure have a tendency

to either reinforce or modify his estimates of his own personal attributes (including his self-esteem), which, in turn, determine future aspirations and goals. This cyclical process continuously makes an impact upon a person's feeling of competence and adequacy.

While this internally oriented process is occuring within the individual, a similar process is operating within the significant others, providing the basis for additional reflections. Out of the significant other's perceptions of the handicapped person's attributes the significant other establishes certain expectations, observes the visually impaired person's performance, judges success with the significant other's own standards, and weighs the significance of the success by his own value system. The process serves as a basis for reinforcing or modifying the significant other's defining attributes of the handicapped individual. With the newly strengthened or revised defining attributes, the cycle begins once more (Tuttle, 1984).

The competence model just described places heavy emphasis on the visually impaired person's self-concept and others' perceptions of his attributes, aspirations and expectations, judgments of goal attainment, standards and values. Opportunities for additional discrepancies occur throughout these parallel processes. The handicapped individual's aspirations, judgements, standards, and values are rarely congruent with the significant other's expectations, judgements, standards, and values.

Problems to Be Resolved:

I contend that a person who is visually impaired has four major problems with which to contend. In order to feel competent and adequate, he must first develop good coping skills and adaptive behaviors. The next problem is to maintain a sense of high self-esteem in the face of predominately negative reflections from others. The third problem centres around the visually impaired person's ability to maintain control over a situation, to perceive alternative courses of action, and to make decisions or choices regarding events in his life. The fourth problem has to do with the negative impact on self-esteem that results from the fact that a visually impaired person, even with the best coping skills and adaptive behaviors, is still dependent on others to accomplish some daily tasks, and as a result, does not appear to be exercising an internal locus of control.

These problems are handled in a variety of ways. Some young or immature handicapped children deny their own perceptions in favor of the signals being received from significant others. Others, particularly during the adolescent or young adult years, exhibit a super-independent attitude trying to prove to the world and themselves that they are fully competent and adequate. Still others are content to remain dependent and compliant indefinitely. There are those who minimize or deny the realistic impact of their visual impairment, choosing rather to refer to an inconvenience or a nuisance and, in extreme cases, pretending as though they had no disability. Some choose to escape or withdraw either physically or emotionally. Still others become hostile and angry, blaming others for their difficulties. Finally, I would be remiss if I did not mention the many who handle their visual impairment in an emotionally mature and responsible manner, recognizing that life for a person with a disability can be rich, full, satisfying, and rewarding.

The Adjusting Process:

Special education teachers need to be aware of the dynamics that impinge upon the affective growth of a visually handicapped child, youth, or young adult. After identifying some goals in counselling, a counselling theory with some of its techniques that are appropriate for the special education teacher is offered for consideration. A discussion of the adjusting process follows, with suggestions regarding particular counselling theories and techniques that seem to be more suitable for each phase. Finally, this section concludes with a summary of the qualities or characteristics of a teacher-counseller.

The Goals of Counselling:

It is my conviction that special education teachers are involved in counselling whether they like it or not. The teacher is able to create the climate for cognitive, affective, and behavioral growth. Frequently, affective growth results as a by-product of working on other tasks and not from a scheduled "counselling session". The teacher-counsellor who is working with handicapped children and youth may want to consider one or more of the following aims that enable the special education student to:

1. Develop adequate coping skills and adaptive behaviors.
2. Work through some of the phases of the adjusting process (discussed later).
3. Gain in self-understanding by clarifying and refining his perception of his personal attributes and his self-concept.
4. Confront and, if necessary, modify his own feelings and attitudes toward himself, toward his visual impairment and toward the non-disabled.
5. Disclose himself to another by sharing his likes and dislikes, his aspirations and expectations, his standards and values.
6. Develop a concern for others, their interests and desires, their joys and frustrations, their standards and values.
7. Understand and enhance relationships with others.
8. Identify and discuss any concerns or problems related to the visual impairment: cause and prognosis, heredity issues, effective coping strategies, management of the public.
9. Improve his self-confidence, self-acceptance, and self esteem.

Although the above list of aims focuses on issues related to the visual impairment, the teacher-counsellor must place these issues in the broader context of growth toward maturity. The disabled individual, along with everyone else, wants to be emotionally healthy, to be fully functioning, to be self-actualized. The following list of characteristics that describe an emotionally healthy, self-actualized person was synthesized from the writings of Ellis (1979), Maslow (1970), Saul (1947), and Tuttle (1984).

1. He is appropriately independent (but not super independent) and responsible with a well-defined standard of ethics.
2. He is interested in and concerned for others and demonstrates good interpersonal skills.
3. He is self-accepting and accepting as well as tolerant of others.
4. He is giving and productive yet able to receive in return.
5. He is more cooperative than competitive and egotistical.
6. He is reality oriented and confident in his own perceptions and judgements.
7. He expects to be successful in his endeavours and expects to be well received by others.
8. He is self-directed with an internal locus of control and internal locus of evaluation, and he is self-motivated toward continued personal growth.

9. He is adverturesome, able to take risks (though not foolhardy), and able to tolerate uncertainty.
10. He is discriminating, adaptible, and flexible.
11. He possesses healthy attitudes and feelings toward his own sexuality.
12. He possesses a good sense of humor and has a large capacity for enjoyment of self, others, and things.
13. He is relatively content with his situation.
14. He needs periods of privacy to pursue his own interests and activities.

A Suggested Approach for the Teacher-Counsellor:

For the special education teacher-counsellor, I would recommend the client-centred or student-centred approach developed by Rogers (1951, 1961). He felt that students have the capacity for self-awareness, self-understanding, and self-direction; for growth, for constructive personal change. Rogers did not develop his approach for working with the mentally ill, but rather for the relatively healthy individual desirous of learning to live more effectively, to be more autonomous and independent. As such, I feel this model fits visually impaired children and young adults for they are not mentally ill but simply struggling to learn how to accommodate to life's demands.

Rogers deals primarily with the here and now and pays little attention to the unconscious. Efforts are directed toward student's gaining self-understanding and acquiring the ability to solve his own problems. The student is given the responsibility for decision-making and setting his own goals and direction. As a result, Rogers has no need for testing, diagnosis, or interpretation.

A student will structure himself according to his perception of his reality. Therefore, he will actualize himself within the reality that he perceives. According to Rogers (1967), there are six characteristics that are both necessary and sufficient for change or growth to take place in the student. They are:

1. Two people are in psychological contact with one another.
2. One (the student) is in a state of inconguence, vulnerable or anxious, ready for change.
3. The other (the teacher) is congruent or integrated.
4. The teacher possesses and exhibits an unconditional positive regard for the student.
5. The teacher possesses and exhibits empathetic understanding of the student's internal frame of reference.
6. The student becomes aware of and experiences the unconditional positive regard and the empathetic understanding.

The teacher-counsellor must be genuine, authentic, and real, no pretenses and no facades. She must communicate respect for and acceptance of the student. Cultivation of the qualities of empathy and understanding are essential. Finally, the teacher-counsellor needs to be warm and caring. At the same time, the student must be open to new experiences, learn to trust in himself, develop an internal locus of evaluation, and be willing to risk making choices or decisions.

The role of the teacher-counsellor may include one or more of the following:

1. Reflect the content and feelings being expressed by the student,
2. Clarify student's messages,
3. Assist student's understanding through teacher's self-disclosure,
4. Engage in "you-me" talk that is concrete and specific especially about personal attributes, aspirations, beliefs, standards, and values,
5. Confront, when necessary, as an invitation for the student to examine discrepancies,
6. Help a student muster his own resources, and
7. Encourage the student to find his own solutions.

There are some safety features of this approach (Corey, 1982) that make it particularly appropriate for special education teachers. The emphasis on listening, respect, and empathy fits with most teachers' capabilities. Dealing with the here and now obviates any need to diagnose or interpret the self-understanding, choices and actions. Since it is primarily non-directive, the teacher can rest assured that the use of this approach can cause no psychological harm.

The Adjusting Process:

People, whether disabled or not, when responding to traumatic events or crises in their lives, tend to experience some or all of the phases of the adjusting process. I do not believe that there is a static state of "adjustment" since people are engaged in a life-long process of growth. Neither do I believe that a visually impaired person adjusts to his disability. Instead, adjusting can be described as the process of responding to life's demands with the added stress of a visual impairment. The disability is simply one of many personal attributes, some representing strengths and others representing limitations, with which the individual faces life's challenges (Tuttle, 1984).

Trauma, physical or social:

The trauma is the event or series of events that produce a sense of disequilibrium, incongruity, or vulnerability making a person anxious or upset. A physical trauma would be the actual onset of a disability while the social trauma results from encountering the social stigma of that disability.

The teacher-counsellor is rarely with the student at the time of a physical trauma. Typically, it's the medical profession and the parents who are present during this crisis and, frequently, neither is prepared to handle the psychological implications. The teacher-counsellor is much more likely to be present during or after a social trauma. An understanding of the adjusting process will enable the teacher to be supportive and understanding.

The question is sometimes raised whether parents and teachers should shield the child from social trauma. If the child is unprepared to handle the crises, then the teacher or parent may want to consider intervening or restructuring the situation. However, if the child has been prepared for either the physical or social trauma, the adjusting process will be less severe and the child will be stronger as a result of working through the phases himself.

Shock and Denial:

Shock is a psychic anesthesia that numbs the mind, preventing disintegration. Denial is one method to escape coping with the requirements and implications of the trauma. As a temporary phase, shock and denial are natural and even healthy responses.

The teacher-counsellor should not attempt to intervene in any active way. Because of the shock and denial, the student is unable to respond cognitively or emotionally. The role of the teacher may be simply to provide some emotional support and physical comfort. If the denial persists, then confrontational techniques would be appropriate.

Mourning and Withdrawal:

As the shock begins to wear off, one begins to become aware of a general state of incongruity or a global sense of loss. This phase is characterized by mourning and self-pity frequently accompanied by withdrawal and

isolation. People who are engaged in self-pity tend to cut themselves off from their own support network. Hostility and anger may begin to emerge and are directed to anyone who happens to be available.

The teacher-counsellor can begin to be a little more active. Most important, she will need to be a good emphathetic listener. In so far as possible, the student needs to have his mental energies redirected off himself toward some enjoyable or constructive activities to reduce the danger of isolation and withdrawal. The teacher-counsellor will want to explain the student's behavior and the dynamics of the adjusting process to family members and other teachers.

Succumbing and Depression:

As the shock continues to wear off, the student begins to ponder the many implications specifically one by one. This phase is characterized by the phrase "I can't". However, the student's perceptions of what he can and can't do are frequently distorted and unrealistic. As a result of the student's pessimistic and negative perceptions of himself and his abilities, he frequently experiences some degree of depression, usually of a temporary nature.

The teacher-counsellor needs to continue to be an empathetic, understanding listener. In addition, some of Ellis's (1967) Rational Emotive Therapy techniques may be appropriate: disputing irrational beliefs, cognitive homework, bibliotherapy, student's employment of new self-statements, and modeling. Some notions from Glasser's (1965) Reality Therapy may also be appropriate: stressing the student's strengths and potentials, development of a success identity, confrontation of irresponsible behavior, accepting no excuses, clarify goals and aspirations, and formulation of a specific plan of action. Finally, the teacher-counsellor, through the use of disabled role models and other techniques, may be able to provide convincing evidence that life is worthwhile, that life as a visually impaired person can be rich, full, and satisfying.

Reassessment and Reaffirmation:

During this phase, a student reassesses his personal attributes, goals, and values. There is a search for a personal attributes, goals, and values. There is a search for a personal identity and for the meaning to life. The student becomes aware that some trauma can be avoided, some can be prevented by restructuring prior circumstances, and still others can be conquered through the development of coping skills.

The teacher-counsellor needs, more than ever, to exhibit acceptance, respect, and understanding. The existential questions regarding meaning and purpose to life, regarding free choice and responsible action may need to be answered. Adler's emphasis on clarifying goals and values may be helpful. Use of Ellis's ABC self-help approach would help students understand the consequences and effects of their rational and irrational beliefs. It's important that the student be able to reaffirm himself as a person and reaffirm the possibilities of life.

Coping and Mobilization:

The coping and mobilization phase focuses on the development of suitable coping skills and adaptive behaviors. To accomplish this, one must mobilize one's internal and external resources. The goal is to enable the student to manage more effectively the daily demands in his physical and social environment. Through improved coping skills, the student can gain self-assurance and self-confidence.

During this phase, the teacher-counsellor is primarily a teacher providing instruction in specific skills and techniques. The approach is behaviorally oriented. The student should be involved in formulating the behavioral goals and objectives. The teacher-counsellor may employ a variety of techniques such as precision teaching for social skills, behavior modeling, role playing, cognitive behavior modification, behavior rehearsals, etc. The student will also need accurate information about his disability: cause, extent of impairment, and prognosis. The teacher-counsellor will take every opportunity to facilitate the student's development of healthy attitudes toward himself and his visual impairment.

Self-acceptance and Self-esteem:

Unfortunately, too many professionals in special education and rehabilitation stop with the coping and mobilization phase with the conviction that their work is done. It is my contention that people can learn to live with their disabilities without ever accepting themselves, much less developing any sense of self-esteem. During this phase, a person learns not only to accept his visual impairment but also to accept himself as a person with a disability, comfortable with himself, at peace with himself, and liking himself. Self-acceptance frees a person to accept others which, in turn, allows the disabled student to be accepted and valued by others--the basis of self-esteem.

The teacher-counsellor will want to focus on the development of strong interpersonal relationship skills. The Transactional Analysis approach (Berne, 1961) offers a context for the student to understand the dynamics of relationships. The teacher-counsellor needs to allow the student time and space to exercise, independently, his newly acquired coping skills. It is often very difficult for the teacher-counsellor to let the student go, to suddenly realize she is no longer needed.

The adjusting sequence just described is a dynamic, continuous process. Every time a person encounters a new psychological situation or unresolved discrepancy, he will cycle back through some or all of the adjusting phases. Unfortunately, there are some individuals who get stuck at a particular phase and remain there for long periods, even a life-time. It is apparent from the above discussion that the needs of individuals vary from one phase to another and, therefore, the approaches of the teacher-counsellor must vary to meet the needs.

Characteristics of the Teacher-Counsellor:

The teacher-counsellor, to be effective, must possess and exhibit certain personal qualities and traits in her own life. The following lists have been adapted from Self-Esteem and Adjusting with Blindness by Tuttle, (1984).

Characteristic attributes of the teacher-counsellor that foster affective growth:

1. She is self-accepting with a healthy self-esteem.
2. She is positive toward others, actively seeking the value and worth in her students.
3. She is not sceptical, cynical, or unduly suspicious of others.
4. She is accepting of her students, their contributions and efforts, their talents and faults, their strengths and weaknesses.
5. She is genuinely and personally interested in each individual, taking time to listen to each.
6. She is able to see things from other people's perspectives thus increasing her capacity for empathy.
7. She possesses good interpersonal skills and is able to resolve conflicts that may arise.
8. She is able to receive as well as to give in personal relationships and is able to teach others to do the same.
9. She is supportive of others.

Characteristic behaviors of the teacher-counsellor:

1. She develops and maintains strong interpersonal relationships with a variety of individuals.
2. She structures experiences so that students can "discover" ideas and relationships for themselves rather than authoritatively imposing her own ideas and views on others.
3. She sets expectations of her students that are in harmony with their talents and abilities.
4. She designs activities for her students that insure maximum opportunity for success.
5. She does not view the student's inability to meet her expectations as a "failure" but rather views it as a positive learning experience for both.
6. She tends to employ criterion referenced measures using the student as his own standard rather than employing norm referenced measures that force comparison and competition with others.
7. She avoids correcting students in public and refrains from using sarcasm in that correction.
8. She actively seeks the ideas and opinions of others.

Characteristic assisting behaviors of the teacher-counsellor:

1. She assists her students to develop good interpersonal skills and relationships.
2. She assists students to understand themselves better, to clarify their perceptions of their personal attributes in a wholesome and accepting atmosphere.
3. She enables her students to present themselves positively, to capitalize on their strengths and inner resources.
4. She assists students by encouraging them with a positive "You can do it" attitude.
5. She assists her students to set realistic aspirations that sometimes means saying "let's try" to an unrealistic aspiration.
6. She facilitates independence, students' doing things for themselves rather than her doing things to or for them.
7. She provides the support necessary to enable her students to recognize and to think through their own problems, to search for alternative solutions, and to choose a course of action.
8. She stimulates her students to mobilize effectively available resources and services.
9. She encourages students to establish and utilize relevant standards and values for measuring their own performances rather than relying on external evaluations.

SUMMARY:

The special education teacher is involved in counselling whether she likes it or not, for it is during those school years that the child's self, self-concept and self-esteem is being formulated. Counselling is seen as the process of assisting students to understand themselves and others, develop good coping skills and adaptive behaviors, and become more independent when dealing with life's demands and solving problems. Based on the reflections model and the competence model for self-esteem, a disabled person more frequently encounters negative reflections and is more frequently deemed less than competent. In response to social and physical traumas, people sequence through some or all of the phases of adjusting and the role of the teacher-counsellor is slightly different at each phase. The student-centred approach developed by Rogers (1951, 1961) offers the soundest and fastest framework of theory and practice for the teacher-counsellor working in special education.

BIBLIOGRAPHY

Berne, E.: Transactionalysis in Psychotherapy. N.Y., Grove Press, 1961.

Coopersmith, S.: The Antecedents of Self-esteem. San Francisco, Freeman, 1967.

Corey, Gerald: Theory and Practice of Counselling and Psychotherapy. Monterey, Brooks/Cole, 1982.

Dobson, James: Hide or Seek. Old Tappan, N.J., Revell, 1974.

Ellis, A.: Rational-emotive Psychotherapy. In D. Arbuckle (Ed), Counselling and Psychotherapy N.Y., McGraw-Hill, 1967.

Ellis, A.: The Theory of Rational-emotive Therapy. In Ellis, and Whiteley (Eds.), Theoretical and Empirical Foundations of Rational-emotive Therapy. Monterey, Ca., Brooks/Cole, 1979.

Fromm, E.: Man for Himself, An Inquiry into the Psychology of Ethics. N.Y., Holt, Rinehart and Winston, 1947.

Gergan, K.J.: The Concept of Self. N.Y.,Holt, Rinehart and Winston, 1971.

Glasser, William,: Reality Therapy. N.Y., Harper and Row, 1965.

Hamachek, D.E.: Encounters with the Self. N.Y., Holt, Rinehart and Winston, 1971.

Horney, K.: Our Inner Conflicts. N.Y., Norton, 1945.

LaBenne, W., and Greene, B.I.: Educational Implications of Self-Concept Theory. Pacific Palisades, Goodyear, 1969.

Kirtley, D.D.: The Psychology of Blindness. Chicago, Nelson-Hall, 1975.

Lowenfeld, B.: Berthold Lowenfeld on Blindness and Blind People. Selected Papers. N.Y., American Foundation for the Blind, 1981.

Maslow, A.H.: Motivation and Personality. N.Y., Harper and Row, 1954, 1970.

Mead, G.H.: Mind, Self and Society. Chicago, University of Chicago, 1934.

Rapp, D.W.: The Developmental Nature of Self-Concept. Hattiesburgh, Miss., Bureau of Educational Research, University of Southern Miss., 1974.

Rogers, C. Client Centered Therapy: Its Current Practice, Implications and Theory. Boston, Houghton Mifflin, 1951.

Rogers, C.: On Becoming a Person. Boston, Houghton Mifflin, 1961.

Rogers, C.: Personality and Interpersonal Relationships. In Koch, S. (Ed.): Psychology: A Study of a Science. Vol. III. N.Y., McGraw-Hill, 1959.

Saul, L.J. Emotional Maturity: The Development and Dynamics of Personality. Philadelphia, Lippincott, 1947.

Stringer, L.A.: A Sense of Self, A Guide to How We Mature. Philadelphia, Temple University Press, 1971.

Tuttle, D.W.: Self-Esteem and Adjusting with Blindness. Springfield, Thomas, 1984.

Wright, B.A.: Physical Disability - A Psychological Approach. N.Y., Harper, 1960.

ELECTRONIC TRAVEL AIDS FOR CHILDREN: ADVANTAGES AND DISADVANTAGES

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I realize that this conference is going to be attended by many different individuals who are here for different reasons. There will be professionals who work in the field of blindness that are here to find answers to questions that haunt them daily in their work. There will also be medical personnel who have a general concern for those patients who can not be helped any further in a medical sense. The knowledge that they gain and the attitude that develops will be of assistance to the visually impaired individual and their parents. And to the parents who will be in attendance: they search for answers to problems and concerns they have for their individual child. For, after all, they do know their child best. I am sure that more than once this week parents will just shake their heads in amazement at how many different opinions can be so strongly generated at a conference for people with a common cause: to better understand blind and visually impaired children in order to foster as full a life as possible for them.

Since the conference attendees are so various, I have decided to present this paper so that it will be of interest to everyone. I will try not to use "jargon" that exists in the field of orientation and mobility. A definition will follow all terms that may not be understood by everyone. I plan to give everyone so much information that they will easily be able to tell others back home just what it was I was trying to say. I also plan to discuss some issues that I am sure will not be agreed upon by everyone. At least, you should be able to understand why I should feel the way I do.

I intend to explain the types of electronic travel aids that are presently on the market and why they would have been invented in the first place. Then, I will discuss possible uses for these aids, their advantages and disadvantages, and relevant studies and/or my own experiences that have brought me to any conclusions that I make. For my own ease in presenting this material, I will discuss this information in age categories: older children, younger children, and infants.

Before I get started, I feel that I should tell you additional information about myself that would not have been included in my introduction. I mainly work with adults but have had considerable experience with children, both within a school for the blind and a public school system. I have instructor training in all of the electronic travel aids that are presently available. I have taught seven people the use of the Laser Cane (one of whom was a child), three people the use of the Mowat Sensor, two people the use of the Sonicguide (one of whom was a child), and have recently been involved in an experiment with a new type of Sonar Aid used by a seven-year-old child. It is this direct experience with blind and visually impaired people that has brought me in front of you today. I must also admit that I have done a lot of additional reading on the topic!

If you in the audience have sight, imagine getting here today with very little or no sight. For those of you who live in Vancouver, it means traveling downtown on a bus and walking over from Granville Street. You also assumedly would have had to cross some streets from your house to the nearest bus stop. If you are from out of town and stayed in the hotel, it only means traveling down a few floors to this conference room--in a hotel that you have never seen before. I surely hope the elevator was marked along with the door jamb of each floor so that you could get off on the floor you wanted. As those of you in the room with limited vision know, it is not always an easy task to travel from one point to another.

Let's hope that you have had the opportunity to take a full course in orientation and mobility prior to having to get here today. You may have been taught how to use a long, white cane and how to improve the efficiency of your remaining senses. Street crossing methods, bus travel, and how to use an unmarked elevator would have all been covered with enough experience and time for you to feel confortable with the techniques. You would have reached your own level of independent travel and, hopefully, would be using those skills on a daily basis. You would be able to travel in any environment which is consistent with those of your training and past experiences.

However, here comes the bad news. It is rare to find any environment that is so consistent that it makes your travel free of stress. Your instructor was so happy the day your cane nearly broke on that unexpected truck that was parked across the sidewalk! "Your cane contacted the truck before you did! That's great!" your instructor yells. But he has forgotten what it feels like to have your heart bounce up and down inside you because you certainly weren't expecting to

"run into a truck." The instructor uses the word "contact" but to your point of view, "run into" better describes the situation. Your instructor also always picked an ideal area in which you could learn best. The instructor is never around to watch you try to travel when you visit your friends in Tuktyukttuk. Or where is he when I am approaching an escalator in a shopping mall from the underneath side? Real life travel situations are never the same as when you were learning.

Therefore, there appears to be a greater need for more protection than the long, white cane is able to provide and for more information than is readily perceivable through the remaining senses. This is why people started looking at developing electronic travel aids as long ago as 1943. The original concept was not to replace sight, but to enhance the amount of information that is perceived by the remaining senses.

Basically, there are two types of electronic travel aids or ETA's. There are aids that serve as obstacle detectors. These would send out either a laser or ultrasonic beam, which would bounce off almost any object that would be situated in a path of the device. On its rebound, the beam would be received back to the aid, which would tell its user of the objects by either beeping or vibrating. An approximate distance can be determined by some of the aids besides the location of the object. Therefore, the user can make an easier decision to move around the truck before the cane makes contact, "runs into," the object.

The most common ETA's that would fit into this category are the Mowat Sensor and the Laser Cane. I shall explain these in more detail later in my presentation. However, there have been other aids developed that would fit into this category of ETA. To name a few: the Pathsounder, the Sun-Ray, the Sonic Pathfinder, the Nottingham Clear Path indicator -- among others.

Most people that use these aids enjoy the fact that they no longer need to deal with cane contacts. Therefore, their travel experiences become less stressful, which for some individuals gives them the motivation or the confidence to travel. I always feel complimented when a student wants to travel for pleasure and not just because he needs to get from point A to point B. Many of my ETA students have enjoyed just going for walks.

Besides the reduction of stress, the obstacle detector ETA's can help the user locate an object that can be used as a

landmark. This landmark that tells the user the location of a particular object may be at a greater distance than can be perceived by the natural senses. Many dog guide users who become disoriented because of the rapid rate a dog likes to travel can gain from using one of these aids. Since it is the role of the dog guide owner to tell the dog where to go, he can better make those decisions based on information received from the ETA.

The obstacle detector ETA can also give the user added protection that is not otherwise available. The long, white cane only protects the user from the waist down. If an object, such as a low awning, is hanging out from a store, the long cane traveller could make head contact with the awning. But an ETA could inform that traveller about the awning before he makes contact.

The second type of electronic travel aid includes those that serve as environmental sensors. These aids work primarily the same as the obstacle detectors: a beam is emitted from the aid, bounces off any objects in its path, is received back to the aid, and this information is displayed to the user. This information tells the user the distance and direction of the object, as it does for obstacle detectors. However, these ETA's inform the individual about the nature of the object. By nature, I mean to say that the information is different if the object is made out of wood, metal, or glass. In other words, it gives you a new vocabulary to interpret what the object actually is. Needless to say, it takes many hours of training to learn this vocabulary. But once learned, it gives the user lots of information. For example, one of my students could get on the subway in Toronto and know by the quality of sound if the seat he was looking at was vacant, occupied, or the occupant was in the process of moving over to make room for him. When seat is vacant, the quality of the environmental sensor informs hinm of the vinyl straight back seat. If occupied, the sensor tells him that the object is no longer flat but very rounded and wearing a softer material than vinyl. Mind you, it takes a skillful individual not to sit on a skinny person wearing a leather jacket!

The most common environmental sensor on the market today is the Sonicguide. There are similar aids, such as the Siemens Spectacles, but they do not give as much information as does the Sonicguide. ETA's such as these can also give the user the same information as the obstacle detectors. Therefore, it provides the same benefits but with the addition of this vast vocabulary.

I must introduce what the ETA's can not do at this time. The purpose of this presentation is not to impress you with the possibilities of these ETA's. None of these aids can give the user warning of the exact location of any drop-off, such as a curb, flight of stairs, or a construction ditch. The Laser Cane does give advanced warning of a drop-off but only at a distance of 6 feet before the traveller arrives. It does not tell him where the actual edge is located. Therefore, the ETA's were invented to be used in conjunction with a long cane or a dog guide.

The exact distance you may be from the object in your path is also not definite. With both Lasers and Ultrasound, there are many variables that interfere with such exactness. For example, the thinner the object is, the closer you need to be to it in order to receive information. Some aids only tell the user that an object is within 30 inches to 6 feet. Obviously, that distance difference could cause confusion in when to get back to your original line of travel once you began to move around it.

Sometimes the aid may give you false information. Lasers are affected by colour, since lasers are actually light beams. So if the tiling in a hallway of a building has wide, black stripes running across it, the Laser Cane would tell you that there were ditches running across the hall. Ultrasound is affected by electrical fields. A sonicguide user may not be able to detect the opening to a jewelry store in a shopping mall because of the field generated by the burglar alarm system.

All of these aids take training in how to use them. The ETA owner needs to learn what the aid can do as well as what it can't do. Even the simplest of these aids can not be fully used without adequate training. And the most complex aids can take up to 90 hours of training in order for the user to begin to get full beneifit from it. However, no matter how long it may take to learn how to use it, any ETA is totally dependent on the ability of its user. At present, there are no travel modes that come with guarantees for safety. Even with following a sighted person's elbow, you are dependent on the alertness of your sighted guide.

In addition to that, using an ETA cannot be isolated from the many other skills that a good traveller needs to have, skills such as being able to mentally map out the environment one is travelling in. Which, of course, is dependent upon having a somewhat complete understanding of the necessary concepts to travel in that environment. ETA's are not taxi cabs.

I would not like to give the impression that my presentation so far has completely covered the uses of electronic travel aids. My time does not permit this. I hope that I have been able to give you a better understanding of what an ETA is and how they can be useful for many people. If any of these aids sound as if it may assist someone you know, I suggest that you contact an orientation and mobility instructor who has been trained to use that ETA. This way you would be able better to determine its appropriateness for that one individual.

Now let us turn to the older school aged child. By this I mean someone who is at least a teenager. They would have a more clearly defined need to travel than would a younger child. Travel needs are great in the upper grades to merely go from classroom to classroom in usually crowded hallways. Most children this age want the independence to go to and from school by themselves and not have to wait for a parent, family member, or friend to take them. Along with such independence comes the liberty to stop at the corner store on the way home to spend lunch money in less nutritious ways. As long as a child within this age group has the social skills, there will be plenty of travel objectives for the student.

A study done in the United States in 1977 by an orientation and mobility instructor, Dorothy Goldie, exposed four junior and senior high school students to both the Laser Cane and the Sonicguide. After equal exposure, all four students chose to be trained on the Laser Cane. Their reasons varied from the fact that the Laser Cane is easier to learn to use to the fact that it was easier to use an aid that is already mounted on a cane. The four students found the Sonicguide interesting but didn't feel that it (the Sonicguide) was necessary to be able to travel from one place to another safely.

The Laser Cane is the same height as a conventional long cane but is heavier due to the housing of the lasers and other electronic parts. Three pencil-thin beams are sent out from just below the user's hand. One beam goes up on an angle to protect the user from the waist up. Detection of a high object is given when the user is five and one-half feet from the object. At this moment a high pitch is given off from the cane. There is a small speaker near the top of the crook of the cane that emits the sound. This point, of course, is closest to the user's ear. There is a volume control so that you can regulate according to the other noise level around you.

The second beam goes out like the first beam, except that this one goes straight out. There is a control that will regulate the distance of the beam to either 15 feet or 8 feet from the user. It is like using a 15 or 18 foot cane. If there is an object in the path, a medium tone is emitted along with a small vibrating pin that is activated on your index finger.

The tone can be turned off so that the user only responds to the vibrating pin. This is most useful when travelling in a crowded shopping mall. No one wants the cane beeping all the time.

The third beam is pointed down towards the ground. As long as the ground is there, the beam is reflected back up to the cane and no sound emits. However, when the user is 6 feet from a set of stairs, a hole, or a curb that is greater than 4 inches, the beam does not get back to the cane which causes it to emit a low tone.

The four students in the study all evaluated their travel experience with the cane as having less stress, which gave them more confidence. Therefore, travelling became easier, especially in unfamiliar surroundings. Their ability to use the device relied heavily on two factors: their basic cane technique (if the cane is held with the beams slightly off, it would detect objects to your side instead of in front of you); and the second factor was their ability to relate to spatial layout (one cannot move around an object unless he can relate to where the object is).

Younger students are not usually introduced to the Laser Cane because they may not have the body co-ordination to use the cane effectively. The grip is quite bulky, which in itself calls for a fairly large hand. A younger child may also have insufficient mobility skills and incomplete sensory skills to use the cane and integrate the additional sensory input.

The Laser Cane may, however, be used as a teaching tool. Because it needs to be held in just the right way, a student who is having problems learning the techniques with a standard cane could be aided by a series of lessons with a Laser Cane. It could also be used to help teach a straighter line of travel.

I have only mentioned the Laser Cane, but an older child could be able to benefit from any of the ETA's. Of course, this would depend upon the individual's needs.

For the younger child who may not have the same demands to travel as an older child, the ETA's no longer could meet the role to assist their travel abilities. A child needs to have certain prerequisite skills before his travel world begins to grow. You cannot send a child to the store until he has the skills to make change, carry the goods home, in addition to using the cane, and many other such skills. Therefore, ETA's can be used as teaching tools for younger children.

The Mowat Sensor could be used as one of these teaching tools. The Mowat Sensor is a small, hand-held device that gives information to the user that pertains to the distance and direction of any particular object. It is about the size of a battery-operated flashlight. Ultrasonic beams are emitted from the Sensor. If these beams contact an object, they bounce off the object and back to the Sensor, which sets it vibrating. There is a distance/vibration ratio that causes it to vibrate more rapidly the closer to the object the user is. Obviously, near and far are concepts that can be reinforced using the Mowat Sensor.

Actually, there are many concepts that can be reinforced in a very positive way for the younger child. I would like to stress the word "reinforced." No ETA, due to the training required to use these devices, can instantly provide a child with complete concept of anything. I am afraid that the area of concepts is not that easy.

However, the Mowat Sensor, among others, is able to put the child in control of his learning experience, which is important for the development of perception. The Mowat Sensor can be used to reinforce such concepts as facing movements, turns, maintaining a line of direction, relocation of position in space, spatial orientation and organization, and the relationship between oneself and other objects. From the incomplete list that I just mentioned, there are many other very important skills that are being reinforced and developed at the same time. For example, since the Mowat Sensor is held in the hand and the beams respond to the direction that it is being pointed, it could be easier to teach the idea of being able to point to an object.

Infants lack a need to travel as do older children and they are not at a verbal level to easily build on conceptual development. However, infants need to be able to reach out and explore their environment so that they may continue their learning process. The Sonicguide may best be suited for this.

The Sonicguide is a pair of glasses that enables the wearer to determine the distance, location, and some character (the new vocabulary of sound to describe the different nature of objects) within an 18 foot radius of the wearer. It is the best example of the environmental sensor described earlier. It can be modified for an infant by changing the glass for a headband that contains the ultrasonic equipment. The range may also be shortened.

Quite a few studies have been conducted using infants as young as 6 months to be exposed to the Sonicguide. These studies

have been conducted in Scotland, New Zealand, the United States, and Canada. It was hoped that the device would help to bridge the gaps in early development and environmental awareness often associated with the lack of vision.

When this was first initiated, you can imagine the reaction it gathered from the workers in the blindness field. The experimenters dwelt on all the positive aspects, while the workers considered all the negative. However, the studies continued.

The most notable of these studies were by Kay and Stelow (1977), Ferrell (1980), Aitken and Bower (1982). The hypotheses for these were most similar. Therefore, I will make comments in each of five hypotheses areas.

Hypothesis #1. - That the Infant Sonciguide provides sensory information that can be assimilated by the infant.

This has been proven in every study that has been conducted. Infants were able to reach for objects in front of them without any auditory introduction. Once the infant has more mobility, he can use the device as an obstacle detector.

These results were not instantaneous. It takes many hours of training to produce such behaviors in these infants, as it does to produce results with the normal development of a visually impaired infant's auditory perception.

Hypothesis #2. - That the Infant Sonicguide will increase the infant's awareness of the environment.

It is simply too soon to make any statements on the overall impressions these children may have on the environment based upon their infant experience with the Sonicguide. To my knowledge, a follow-up study of the same children has not been completed. In one study, long-term was considered two years. This is not long enough to adequately assess the difference that may exist in the child's conceptual understanding of the environment.

I am aware of a long-term involvement in Canada. A girl from Ontario was introduced to the aid at 6 months. She is presently seven and is still involved in using the aid for selected activities. As an infant, she demonstrated the ability to reach for objects and follow moving objects. As a toddler, she played modified games of basketball and catch with her parents, using the aid. She could successfully move through a maze using the aid's information as an obstacle detector.

However, presently she does not use the aid constantly for any given task. She would still be considered by a trained mobility instructor as learning the use of the aid. Her mobility skills are far greater than her Sonicguide skills. I am not convinced that her infancy experience made it easier for her to acquire the mobility skills.

She always received a lot of input in each area prior to the expected results. Always, she performed with success the isolated task that was required. However, I have not seen an example of her having integrated the aid into her daily life.

Hypothesis #3. - That the Infant Sonicguide give normal milestones to the infant users.

This was not the case in any of the studies. A few of the infants met milestones early for a visually impaired infant. But no one met the milestone for an average sighted infant.

All of these studies use very small numbers of participants. The largest studies used only 10 infants. However, this was for the short-term aspect of the research, three days.

There is also rarely a control group to better compare the ability of the Infant Sonicguide to produce earlier results. Some of the children were older when they were introduced to the device: over two years old. Some delay in the milestones would have already been established. This makes it impossible to determine the results of the aid in achieving continued milestones.

Hypothesis #4. - That the Infant Sonicguide will reduce stereotypic behaviors.

Most of the children showed a reduction of these behaviors when the aid was worn. After all, who needs to rock when the device produces so much stimulation for the wearer.

The use of the aid could produce more normal head movements. Since it is head-bound and only responds to objects in front of the aid, the infant modeled a more normal eye contact than other visually impaired infants. Following a moving object can produce a head movement from the neck, which most visually impaired children do not do.

Some of the children, however, did begin other behaviors that stem from wearing the device. For example, some older infants enjoyed the sounds produced by the aid. Therefore, they would move objects, like beachballs, up towards the aid's emitting screen to produce a sudden lower pitch sound. Actually, a

co-worker of mine used to "play tunes" on his Sonicguide while under blindfold. "Three Blind Mice" was one of his favourite tunes.

Hypothesis #5. - That performance without the Infant Sonicguide is the same as wearing it.

This has not yet happened. As mentioned earlier, the girl from Ontario uses the aid for given situations but has not integrated it into her lifestyle. I have not seen evidence of the integration of any skills either. Most of the infants who decreased stereotypic behaviors resorted back to the same behaviors when the device was taken off. Sonicguide information is unique and does not have a definite carry-over.

Studies with the Infant Sonicguide have proven that infants have the ability to use the device. However, it is not known how useful the device may be in the development of these individuals. More research is obviously needed. I will state, however, that I feel the studies have shown that there isn't an obvious drawback to an infant's use of the Sonicguide. The added attention itself may help to stimulate the infant to learn.

ETA's for children of any age may be exceedingly important for that child. I am a firm believer that the right aid for the right child is a very positive step. But, how do you consider if the child is right for a particular aid?

I feel that need is the greatest determining factor. If there isn't an avenue for the child to incorporate the use of an aid into his daily routine, then there is no need. I have seen situations where a child, producing resistance is encouraged to participate in the Sonicguide skill-building exercise, which is the purpose of the lesson. Once all objectives are achieved and the aid is removed, the child waves his arms in a scanning pattern to find his cat for a play time. Why couldn't the aid be used to locate the whereabouts of the cat? Obviously, this child does not use the aid because he is not convinced of a need.

One final comment. I feel strongly that any ETA should be taught by those individuals who best know the operation of the device and who know the child learning it. This implies that infant research needs to be conducted by a team of individuals including parents, children's workers, ETA training specialists, and the researchers. Researchers alone do not produce integrated skills.

I hope that when you imagine your route home today while under blindfold, that you will find it easier using an ETA that is geared to your own individual needs.

REFERENCES:

1) Aitken, S. and Bower, T.G.R. The use of the Sonicguide in infancy. Journal of Visual Impairment and Blindness, 1982, 72, 91 - 100.

2) Ferrell, K.A. Can infants use the Sonicguide? Two years experience of Project VIEW! Journal of Visual Impairment and Blindness, 1980, 74, 209 - 220.

3) Kay, L., and Stelow, E. Blind babies need specially designed aids. New Scientist, 1977, 73, 709 - 712.

WHAT HAPPENS WHEN MY COMPUTER AID BREAKS

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"The history of technology is the history of the invention of hammers and the subsequent search for heads to bang with them." (Psychiatrist - Matthew P. Dumont - 1973).

The topic of computers and the disabled is very popular these days. Indeed the potential of computer use by the disabled is just beginning to be realized, and the computer is being viewed as the "great equalizer". At last, physical limitations need not dictate equality of opportunity. An active mind complemented by a very smart "slave" can achieve unheard of levels of independence in spite of sensory of physical impairments. But, is computer technology creating more obstacles than it is removing?

There can be no question that computers are here to stay. After all they are marvelously efficient at high speed manipulation of data and they do what we tell them to do.

There is no question that each of our lives has been positively affected by the computer age. Information of any kind is a "button press" away. Energy saving computers, life support computers, air traffic control computers and public information computers are examples of the usefulness of the new technology.

There is also no question that many visually impaired persons have successfully used computers in their career. In fact, if a thorough study was done, it would likely find that the percentage of visually impaired people using computer technology in their career is as high as the percentage of the general public, and most likely to exceed it very soon.

These are all excellent reasons to feel very positive about the future of computers and the visually impaired. I am certainly excited by this future. But I also have some reservations about a few severe pitfalls that we must first address.

Regardless of how much we extol the virtues of the computer, it is, by itself, quite useless to the majority of visually impaired people. Typically computers are accessed through typing and reading, and one must be able to do both to use them. Enter the first obstacle.

Most visually impaired people need a second tool that works harmoniously and swiftly with the first in order to make full use of the wizardry. These tools are being developed and improved upon daily, using braille, large print, or speech as alternative methods of accessing the computer. The current technology is very good and improving extremely quickly.

This however, presents a few more problems. How do you keep up with these improvements? Which is better, braille or speech? Should I get something now or wait for the new one next week? How much will it cost? How long will it take to get here?

In spite of the difficulty in answering the foregoing, the fact remains that a visually impaired computer user must learn to use two tools not just one. A good example of this dual learning is of the person who decides to use a "refreshable braille" device to control data input to and output from a computer. Although all the current devices have well documented instructions, they are still computers. They require you to use a special coding system for maintaining control. They also require special and variable communication links between themselves and the host computer. Similarly, the host computer presents the same demands to the user.

The second pitfall that people face with computers is the familiar problem of what and when to buy. The computer is a tool, a very smart tool, and nothing more. It can be a whole lot less however, if the reasons for getting one are not carefully considered. If you need one to balance your cheque book, your name must be J. Paul Getty. If you need one to do your correspondence, you either have physician's handwriting or a telephone directory full of relatives. If you need one to play games, then you should likely consult a recreation therapist. However, if you want to do all three, manage vast amounts of varied data, do complex mathematical calculations, and "talk" with other computers, then you are probably ready for a computer. The axiom here is find the programs that do what you want and then get the machine that makes those programs work. Too often people buy the machine first only to find out it will not do what they want.

Alternatively, people fall victim to the third pitfall, "overkill". If you are in the market for a toaster you know what you want, or do you? You eat two pieces of toast every morning except Sunday, when you have four. Why would you every buy a four, or worse an eight slice toaster? The same is true of a computer. If you have escaped pitfall two, then be wary of the computer salesman who suggests you buy a

computer that has "512K with six serial ports, one parallel port, extended graphics and makes eight slices of toast when your relatives visit."

Finally, the most subtle, and, I think, most important pitfall to avoid is dependency. How many of us still do long division by hand? Why not just use the pocket calculator, right? But the batteries are dead and you must finish a project for work that requires dividing large numbers. Can you still do it, or do you go out for more batteries?

The nature of computers is that it feeds our desire for making things easier and more convenient. This human tendency makes us more dependent. Anything that disrupts our convenience irrates us, or even can make us panic. However, the answer to the question "What Happens When My Computer Aid Breaks?" is not - PANIC. On the contrary, the answer is be prepared. Be prepared for learning how two different machines work and how they work together. Be prepared for periodic breakdowns and "down times". Be prepared for changing and expanding technology. Be prepared to always ask more questions than there are likely answers. Be prepared to seek help. Be prepared for expenses which are sometimes considerable.

In short, avoid the pitfalls, plan for the worst, and be prepared to use the computer as a tool. Remember, you may someday need to use it to "hammer" in a nail!

VISUALLY IMPAIRED CHILDREN AND THEIR SIBLINGS

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Because blindness is not a required reportable illness in the United States, the incidence of blindness is not accurately known. Consequently it is difficult to make even a conservative estimate of the number of emotionally disturbed blind children who are in need of psychological help.

The total investigative approach of blind children and their families has been a development of the past thirty to forty years, with most of the research work being reported in the past twenty five years.

Recently there have been studies done regarding psychiatric disorders and the risk of developmental deviations in the blind and visually handicapped. The incidence is relatively high as compared to sighted children. Some have estimated that it is six to seven times more prevalent in these children, and the percentages range from 30 to 50% of blind and visually handicapped children having serious psychological problems which should receive professional help.

Many blind children do display the same features as autistic children, and consequently confuse the observer. Most of the visually handicapped children who display these features are not autistic, though they are not exempt from this diagnostic category. These mannerisms are rocking, hand-flapping, spinning, gesturing, toe walking, repetitive speech, echolalia, etc. Often the differential diagnosis is most difficult, and the true measure of the severity of the child's illness is the ability of the child to respond to professional intervention.

One must remember that the blind and visually handicapped child can have the same psychological problems as sighted children, and there is no specific psychological problem which is exclusive to the blind or visually handicapped. Totally blind children usually have more severe problems than partially sighted children. Children who have lost their vision during childhood usually have less severe problems than either of the former.

In my experience with the blind children at the Blind Childrens Centre, I will state that the majority of the children do have some degree of disturbance which could benefit from professional intervention. The diagnosis could range from a simple adjustment reaction which could easily be handled, to the most serious, such as total psychosis. The sooner the child and parents are seen the better are the results. The earlier psychotherapy is instituted with the disturbed blind child, the greater the chance of therapeutic improvement. At the Blind Childrens Centre, the child may receive individual therapy, but the success of treatment is the result of the total team approach, i.e. Child Development Specialist, Social Worker, Psychologist, Teacher, Counsellor, Educational Specialist, Nurse, Kitchen Staff, Volunteer, Mobility Teacher, etc.

Blind and visually handicapped infants and children display varying degrees of ego disturbance. They also may have little or no concept of body image. This reinforces how important early intervention is for the child and his parents. Many of the older visually handicapped children who come to the Centre are still functioning in a most infantile manner.

It is most important to get the child and parents involved in a supportive therapeutic program. It is also important to be aware of the ramifications for the siblings and other members of the family. The psychological trauma of having a blind or visually handicapped youngster not only affects the parents, but also seriously affects the siblings and other members of the family involved in the child's care. Too often the siblings are not included in a treatment program by the professional, and unless they are involved, these children often display emotional problems which seriously affect their own development. The siblings display many different symptoms which include pseudo maturity, especially in relationship to the blind child, passive, too good, behavior, poor peer relationships, hyperactivity, devious expression of their feelings, denial of their feelings, poor school adjustment, nightmares, fears, etc. Because of the parents' diminished capacity to give to the siblings emotionally, as a result of the psychological and physical demands placed upon them, the brothers and sisters are often forced to assume a role that is quite uncomfortable. For example, there might be a two year old who is responsible for leading, guiding, helping and giving to an older blind sibling. These children often fear to express any negative feelings regarding the blind youngster for fear of disapproval, anger or rejection by the parents. Many of these children take on an adult parenting role long before they are emotionally or

psychologically prepared for this role. These children also have expressed, when given an opportunity to state their true feelings, that they do feel emotionally short-changed in spite of the genuine and deep love given by their parents.

In my work with these children, the majority of them display the features of passive, too good, overly mature, behavior within the family. I feel that many of the siblings' psychological problems can be eliminated or avoided if the parents are aware of the pitfalls and are helped to allow these children to express healthy feelings. It is also most important that the parents are aware that the very good behavior is often not the healthiest behavior for the brothers and sisters.

If there are aunts, uncles, grandparents, etc. who are intimately involved in the day to day care of the blind child, they too should be included in the program. We have frequently noticed that grandmothers who have much of the daily care of the youngster become overprotective, and so symbiotically involved with the blind child, that they infantilize the child who then cannot progress.

The reverse can be true in families too. Relatives who were previously supportive and helpful may withdraw from the family picture due to their inability to be comfortable with the blind and handicapped child. It has been my experience that with a little bit of understanding and supportive help most of these obstacles can be overcome.

AN APPROACH TO THE AUDIOLOGIC ASSESSMENT OF MULTI-HANDICAPPED DEAF-BLIND CHILDREN

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INTRODUCTION

Following the Rubella (German measles) epidemic of the mid 1960's, approximately 30,000 children were born to mothers who had contracted this disease during pregnancy. It has been estimated that 5,000 deaf-blind children were born in the United States during that time. In addition, medical science has inadvertently contributed to the number of children born with multihandicaps by reducing infant mortality and controlling infections.

We were first introduced to deaf-blind children ten years ago as part of the visually impaired/multihandicaps diagnostic team at the University of Washington. We were faced with one of two situations:

1. children that were brought to us from Alaska, Washington, Oregon and Idaho for a single audiologic evaluation, or

2. a situation in which the hearing evaluation occurred on site at various institutions and school programs throughout the Northwestern United States.

We later served as audiology consultants to the Northwest Regional Deaf-Blind Centre and the Washington State Programs for Deaf-Blind Children. As consultants, we assessed children at various schools using small-step conditioning programs, serial testing and the assistance of the educational staff. We found success with these children when a positive attitude, a conditioning program and a team approach was utilized.

Due to the complex nature of multisensory handicaps, visual and hearing handicapped children have traditionally gained reputations as being difficult to assess. To many educators and professionals, the deaf-blind label is fraught with terrifying connotations and often one needs to make a personal decision as to whether their efforts can do justice to this population. Some people tend to think of deaf-blind children as always being low-functioning, mentally retarded and generally noncompliant. Others think of an intelligent person who is isolated by the vision and hearing deficits. Many professionals show initial confusion or fear of failure in regards to working with this population. We remember thinking, prior to our first experience, that our reputations had been very good up until now! Our experience, however, has shown us that these initial negative feelings are unfounded. Most of the children who are labeled "deaf-blind" are rarely totally deaf or totally blind. Most commonly, the children we see are hard of hearing with field cuts or tunnel vision.

These multihandicapped/sensory-impaired children usually have enough sensory functioning to establish a basis for a conditioning paradigm if a proper approach is utilized. We have found that all conditioning programs require a waiting posture, an adequate stimulus, a consistent response and an appropriate reinforcer. These conditioning sessions sometimes continue for long periods of time before a child can be assessed. However, the time involved is well spent since the conditioned response allows accurate assessment and can be expanded to other educational areas, such as improved communication skills. The elements of conditioning will be explained in our paper and demonstrated during the slide presentation.

Certainly, if we consider audiology and special education to be professions in which we can express creativity, then the conditioning and assessment of the deaf-blind child is the essence of that thinking. We have found that many of the suspect deaf-blind children have not been given appropriate assessments, have records which are inaccurate and are often misunderstood and misdiagnosed. Children labeled as hard-to-test sometimes carry that label with them throughout their education, even when the label is not appropriate. It is not our intention today to present an academic treatise on this subject, but to explain our philosophy and approach to the auditory conditioning, audiologic assessment and interpretation of test results with low-functioning, deaf-blind children.

HEARING ASSESSMENT

Hearing assessment with multihandicapped deaf-blind children can be broken down into two basic approaches. These are: the electrophysiologic and behavioral approaches to hearing measurement. In electrophysiologic testing, children assume a passive role in the test situation and, using electrodes on the scalp, electricity from neural generators in the brain is recorded. In the behavioral approach, children produce overt responses, either conditioned or unconditioned, and are active participants in the test situation. With some children, out of necessity, both approaches may be appropriate for obtaining the maximum amount of information regarding hearing status.

There are advantages and disadvantages to each approach. For the electrophysiologic approach, the advantages are:

1. it is rapid and information can usually be obtained in one test session;
2. for children who are unable to sit quietly, sedation can be used and, in fact, is often necessary;
3. electrophysiologic responses are "objective" responses and do not require participation of the child.

The disadvantages to the electrophysiologic approach are:

1. both the equipment and the lengthy test sessions are expensive;
2. not all frequencies can be assessed;
3. medical supervision is required for the administration of sedation and the monitoring of the sedated child;
4. equipment is often not readily available except in large population centres; and
5. the electrophysiologic approach assesses only the peripheral mechanism which provides no information regarding more central problems or the processing of auditory information.

For the behavioral approach the advantages are:

1. it is the best way to determine "hearing" since the child must somehow process auditory information to produce a response;
2. if conditioning is successfully used, the child has shown the ability to learn a task related to an auditory signal;
3. equipment for this type of testing is readily available and relatively inexpensive; and
4. all frequencies can be tested at levels which can be compared to normative values.

The disadvantages to the behavioral approach area:

1. it is time consuming to condition children; and
2. particularly for those who are multihandicapped deaf-blind, it is not easy to get accurate behavioral information.

We have chosen the behavioral approach as the method of choice in assessing hearing in multihandicapped deaf-blind children. In addition to information regarding hearing status, it provides the audiologist, as well as the educational staff, with broad information regarding the general functioning of the child. While it is time consuming and difficult, we believe that by using systematic conditioning paradigms it is a feasible approach with many sensory-impaired children. On many occasions we do combine electrophysiolgic responses with the behavioral evaluation but only when the behavioral approach yields incomplete information regarding a child's hearing levels.

Prior to our discussion of the behavioral hearing assessment approach, we would like to present some brief information on the two electrophysiologic tools that we most often use in conjunction with the behavioral testing.

Immittance Audiometry

Immittance audiometry is an electrophysiologic procedure that provides an objective assessment of the function of the conductive part of the ear, that is, the outer ear as well as the middle ear and eardrum. Immittance audiometry has two components, tympanometry and acoustic reflex measurement.

Tympanometry measures the mobility of the ear drum by detecting its stiffness or compliance characteristics. This procedure is not a test of hearing but is an adjunct to hearing testing. From this test we can infer whether a given hearing loss might be primarily a conductive type of loss (which is, by and large, medically reversible) or a sensori-neural loss (which is primarily a permanent type). Briefly, a small, rubber probe is placed tightly in the ear canal and the air pressure against the ear drum is varied slightly. In simple terms, the equipment we use for this testing reveals whether the eardrum and middle-ear mechanism is stiffer than normal or has normal mobility. If it is adnormally stiff, the air pressure variations will have little effect on the position of the eardrum, a condition which could, for example, be caused by an ear infection with accompanying fluid in the middle ear. On the other hand, if it is abnormally mobile, it may be a result of broken or

dislodged bones in the middle ear.

This test is an indication of where along the conductive pathway a problem may exist and, when abnormal, results in a medical referral. The actual diagnosis of the underlying pathology is then made by a physician.

The acoustic reflex is the contraction of a small muscle in the middle ear due to the presentation of sounds which are perceived as loud by the patient. The presence of this reflex is detected using the same equipment as is used for tympanometry and, in fact, is done at the same time using the probe tip in the ear canal. The detection of this reflex requires a normal tympanogram for that ear since the contraction of the muscle can only be observed in a compliant middle ear system.

From this test we can infer some information regarding hearing status. That is, the patient must hear the sound and perceive it as loud in order to trigger the reflex. However, it is possible to have a substantial amount of hearing loss and still have an acoustic reflex. Clearly we can differentiate those with some hearing from those with none. Coupled with results of behavioral testing, however, we have a very strong test battery for the presence of hearing impairment.

Auditory Brainstem Response (ABR)

The auditory brainstem response (ABR) is the recording of electrical potentials or voltages from the scalp, like a EEG test. These responses come from the VIIIth nerve and brainstem, and require a functioning middle and inner ear in order to be generated. Generally, the patient is sleeping or sedated during the test. The electrodes are taped to the skin at either the forehead or the top of the head as well as behind each ear. Brief stimuli, like clicks or tone pips, are presented through earphones placed over each ear. A computer is used to sum activity from many stimulus presentations in order to generate each brainstem response. The stimuli can be presented very rapidly and responses can be obtained every few minutes. The entire test, including sedation, takes about two to three hours. Once responses are obtained, the latency (or time characteristic) as well as the amplitude (or size) of the responses are measured. Based on previous studies of normal and abnormally hearing persons, these latency and amplitude values can then be related to decibels of hearing above threshold. Hearing levels can be estimated with fair accuracy from these responses.

The ABR is not without its limitations, however. One drawback is that it is useful only for the assessment of high frequency hearing. Little or no information regarding low-frequency status is available by this procedure, although many deaf-blind individuals have residual hearing only in the low frequencies. Another limitation is that the ABR requires normal neurologic function to generate the synchronous neural firings for proper response recording. Neurologically impaired subjects may reveal abnormal or even absent responses and yet still have normal hearing.

Nonetheless, the ABR is the most powerful electrophysiologic test of hearing available to us today. Its strength, however, lies in its use in conjunction with a complete behavioral assessment, as well as tympanometry and acoustic reflex testing.

Behavioral Assessment

The process of behavioral assessment is made up of several levels of testing, and some diagnostic decisions can be made early in this process.

The first step in this process is to gather a careful case history combined with informal observation in the classroom. It is sometimes possible to rule out children as being hearing impaired based on this information. During the informal observation, we focus on whether or not the child is using his or her hearing and also note whether the child is responsive to other modes of stimulation such as visual or tactile. If the child does not appear to respond to sound, we begin to gather information on motor ability and possible reinforcers for use in a subsequent conditioning program. Evidence that the child may have some hearing includes localizing a sound source, ceasing behavior in the presence of sound, startling to loud sounds, and other changes of behavior that are related to auditory signals. Sometimes the case history and informal observation, combined with a brief audiologic evaluation, can strongly indicate the presence of hearing within normal limits.

The behavioral audiologic evaluation is basically made up of two separate approaches. The first approach, behavioral observation audiometry (BOA) utilizes unconditioned responses, and places heavy reliance on reflexive type behaviors which are observed in the child. The second approach utilizes a conditioning procedure in which a specific, learned task is utilized as the response mode.

The audiologic evaluation might begin with a BOA approach in which auditory signals are presented via loudspeakers and the child's unconditioned behaviors are observed and recorded by the examiners. Common behaviors which might be observed include: localization to a sound source, evidence of sound awareness such as eye blink, eye widening, limb movement, or cessation of ongoing behavior, and, to high intensity signals, startle responses. The primary usefulness of the BOA approach is to generally categorize children into extreme positions along a continuum of hearing behaviors, from those children who are very responsive to low level sounds, to children who are not responsive to auditory stimuli at all.

Those multihandicapped children who are responsive to auditory stimuli and show, for example, the following behaviors:

1. Response to sound with some sort of consistent behavioral action at low intensity levels;
2. Consistently startles to loud sounds;
3. Normal tympanograms; and
4. Normal acoustic reflexes,

can be thought to have hearing which is within normal limits and which is adequate for communication development.

On the other hand, those children who show:

1. No behavioral responses to auditory stimuli;
2. No startle or reflexive responses to loud stimuli;
3. Normal tympanograms but no acoustic reflexes,

are felt to be clearly in the hearing-impaired category. The major limitation of BOA is that for those in this hearing-impaired category, the actual hearing level in decibels cannot be accurately estimated. There is great variability in the intensity of the signal necessary to elicit unconditioned responses among normals and hearing impaired individuals and in some cases, there is an overlap between these two populations. That is to say, developmentally-delayed children with normal hearing may initiate responses to sound at the same level as hearing-impaired children.

Our experience has shown that a large number of multihandicapped/deaf-blind children cannot be simply categorized using BOA as either normal or hearing impaired. But, rather, fall into a large grey area by revealing such auditory behaviors as:

1. Inconsistent responses to sound;
2. No behavioral responses to sound but normal acoustic reflexes;
3. Responses to sound in the classroom (observed informally) but no responses in a test situation; and/or
4. Normal startle responses to high-level signals but no responses to moderate or low-level signals and no evidence that the child uses his or her hearing.

For this substantial patient population, we believe that the conditioning approach is strongly indicated. This approach allows us to develop a definitive response pattern and allows for a more accurate hearing assessment through the use of a distinct and easily observed response action.

AUDITORY CONDITIONING

The first step toward successful conditioning is a positive attitude. The assessment team members must be patient and willing to approach the child with a small step program and not rush the conditioning process. They should plan many short conditioning sessions for the child. When you begin to work with a deaf-blind child, you must break down each task into a very small step process and be prepared to work on each step for a long period of time. Short sessions will give the educator opportunities to shape behaviors without reaching a high frustation level for the child and for the professional.

Stimulus

Since we are trying to shape the child's behavior for an audiologic evaluation, on the surface, it would seem appropriate to choose an auditory stimulus. In reality, since the child is of unknown hearing status, we have found it beneficial to combine the auditory stimulation with an accompanying vibro-tactile cue. We accomplish this through the use of high-intensity, low-frequency, auditory signals which, when presented through a loud speaker, carry both auditory and vibro-tactile information. In some cases, prior to auditory conditioning, we have initially shaped the behavior of deaf-blind children by teaching them to respond to purely tactile stimulation through the use of a hairdryer or physical touch. Once the child has learned to respond to both auditory and tactile stimulation, we alter the intensity or frequency of the presentations to eliminate the tactile portion of the stimulus. In this way we can then observe the child's responses, if any, to auditory signals alone. It is then possible to probe for auditory threshold without the accompaning tactile cue. It is very revealing to watch some

deaf-blind children respond only when tactile cues are present, demonstrate a cessation of response behavior when only the auditory stimulus is used, and reinitiate responses when the presence of the tactile cue is resumed.

Waiting Posture

A waiting posture is also a key element of the conditioning paradigm. The waiting posture can be defined as a position where the child indicates to the examiner that he or she is in a ready-state to receive a stimulus. For example, in the standard play audiometry procedure, a normal five-year-old might be taught to place a block up to his/her ear and then place the block in a can when a tone is perceived. The waiting posture is holding the block to the ear. This signals the examiner that the child is listening and ready to respond. The waiting posture also helps the child focus on the task. With low-functioning children, the waiting posture may be as simple as hands on lap, or sitting quietly. Obviously, the child must be able to maintain the waiting posture long enough for the audiologist to probe for threshold and be taught to respond only when a stimulus is perceived. It is important not to teach the child that the waiting posture immediately leads to a response. The child must wait long enough so that presentations can be varied from a few seconds to many seconds. The examiner must vary the presentation of the stimulus during the waiting phase so as not to teach an automatic response without being cued by the stimulus. This could lead to a high amount of false-positive responses which would invalidate the test session. The child must be shaped to only respond in the presence of the stimulus and not demonstrate the response behavior in the absence of the auditory signal.

The Response

A key to successful conditioning is the selection of a learned response that is tied to the onset of the stimulus and can be differentiated from ongoing behavior. In discovering an appropriate response, the examiner must often work with the teacher, classroom aid, physical therapist or other members of the educational team to select an appropriate motor behavior. With some children, we have used a headturn response, a reaching response, arm raise, foot movement or leg swing depending on the ability of the child. It is crucial to know the child's motoric ability and functioning level. The method of teaching the response is also important. Initially, the examiner must show the child when and how to respond, slowly decreasing the assistance until the child appropriately responds on his or her own. For example, with an arm reach

response, the examiner will eventually extinguish the constant touching of the arm by moving toward a nudge at the elbow to initiate the appropriate response. Eventually, the child will be taught to enter the waiting posture; wait until the stimulus is presented and perceived; and respond in order to receive the reinforcer.

Reinforcement

The next major stage of conditioning involves the selection of reinforcement. This can be a difficult decision. It is crucial that the examiner knows the child well enough to determine what is reinforcing. Again, the educational staff must help to determine various reinforcers. Give the educational staff ownership in the conditioning process. Ask teachers and classroom aides for suggestions. Talk to parents and/or cottage staff for additional ideas. Look toward the physical or occupational therapist for support. The educational staff spends a great deal of ongoing time with the children and knows their unique likes and dislikes.

Some children prefer vibration, light, social praise, juice, food bits and/or interesting toys. We have found that a squirt gun filled with juice can be an efficient tangible reinforcer. We have also found that some children will not habituate as quickly when different reinforcers are used rather than the same one time after time. Be creative in trying new reinforcers or modifying established rewards.

Controls

When determining if multihandicapped children are conditioned and ready for a formal test, it is important to note if false-positive responses are occurring (ie., random responses without a stimulus cue). This can easily be monitored by using control intervals. A control interval is a time-frame during which it is recorded by the examiners whether the child responds in the absence of a stimulus. Approximately 25% of the presentations during the audiologic exam are control intervals. This helps to monitor whether the child is conditioned and responding appropriately. We have seen some children who learn to wait for a very brief time and automatically go from the waiting posture to the response whether a stimulus is present or not. If a stimulus is always presented immediately after the child enters the waiting posture, it would appear to the naive observer that the child is responding appropriately. In reality, the responses are likely random and more closely tied to the waiting posture than the stimulus cue.

Multisensory Reinforcement Box

One of our most successful approaches has been through the use of a device that produces vibration, light, and sound. Each stimulus can be adjusted to be presented independently or in combination. The sound can be altered for frequency and intensity. The device is built in a briefcase for easy portability. There is currently a research assessment project at the Child Development and Mental Retardation Centre, University of Washington, with Dr. Marie Thompson a professor of Special Education, where this equipment has been developed and tested with deaf-blind youngsters. We have found this equipment to be very successful as a reinforcer. It can be controlled through either a foot switch or hand-held button. The vibration and blinking light serve as reinforcers for many visual/hearing-impaired children.

During the past five years we have worked on conditioning programs for deaf-blind children with the educational staff at the Washington State School for the Blind. Ms. Jean Beary-Stolle, the speech pathologist at the State School, has noted the following suggestions for establishing conditioning with the reinforcement box.

1. Determine if the child is reinforced by or at least shows interest in lights and/or vibration.

   This may be determined with penlights and hand-held vibrators, as well as, with "the box". Will the child follow the light or reach for the vibrator or light, etc.?

2. Will the child tolerate wearing earphones?

   This step is not mandatory if sound-field testing is available but better test results can be found if each ear can be tested separately, ie., through earphones.

   To train this gradually, get the child to wear earphones for other pleasurable activities first. Some examples include having the child listen to music, wearing earphones that are plugged into a record player or tape deck. Or if the child responds to voices better, use auditory trainers and have the teacher or the child vocalize or talk into the microphone. The new "Walkman" types of radios and tape players are also excellent for training purposes. They usually come with softer and lighter headphones that are less threatening to children.

If the child does not respond well to sounds, have him participate in his favorite activities, such as, snack time or play time, with a favorite toy while wearing a set of earphones such as those used with auditory trainers, radios, etc. In conditioning this activity, gradually increase the amount of time the child is expected to wear the earphone from moments to minutes at a sitting.

If the child is very resistant and cries or rebels at the sight or touch of the phones repeatedly, don't worry about conditioning at this point. Do not let this activity be associated with bad feelings or tantrums. The purpose of the training will be defeated if the child cannot enjoy the use of the earphones.

3. Familiarize yourself with the box before introducing it to the child.

Get to know the intensities and frequencies that the box will produce. Also the lights may be adjusted to blink at different intervals separate from the control for vibration and frequency. Find out how you can produce a sound without lights. This is important for producing a sound stimulus alone. Vibration and intensity of the tones produced are in the same control; also, high frequency sounds produce very little vibration.

4. When a child can sit at a table, introduce "the box"

It is necessary for the child to sit and attend to the box. Short training sessions held two times a day may be more beneficial than requiring a child to sit for an extended period of time daily. Therefore, it is suggested that once equipment is set up and the child is at the table, conditioning for 5 - 10 minutes each session will keep the process novel and interesting.

5. Shape the child's attention to the box as a response to tones presented.

a) Present the tones without lights or vibration while the child's hands rest on his own lap or beside the box. Do not allow the child to touch the box or panel until after the tone is presented. (The whole box vibrates with the presentation of low-frequency tones. It may also vibrate the table ... a rubber mat placed under the box often helps remedy this problem. It would be difficult to know if the child

is allowed to rest his hands on the box between tone presentations.) A device, such as a knob, may be made for the child to hold to wait for tones as well. This waiting and ready posture is vital for a good assessment. The child thus indicates just when he hears the tones and eliminates many false positive responses to the stimuli.

b) Take the child's hand after the tone is presented and place it on the panel. At the same time turn on the vibration and/or lights that the child has shown interest in. Direct the child's line of vision (if he has useful vision) to the lights as the child leaves his hand on the panel.

c) Repeat this procedure with various frequencies requiring some waiting between stimuli. After four or five attempts to shape the desired response behavior, allow the child to respond on his own from the waiting posture. If he does not respond, tap his elbow or drop his hand near the panel of the box to cue the correct response.

d) Gradually fade out the cues at sufficient intensity levels of the box. It may help to add another reinforcer to the vibration or lights with some children, (ie., a bite of ice cream or praise when the child appropriately responds on his own. etc.). Sufficient intensity levels for stimulation should be those loud enough for the child to react, yet not so intense as to startle him. Sounds at intensity levels where responses (localization, vocalization, cessation of behavior, etc.) have been seen should be used during initial training sessions.

6. <u>When spontaneous responses are witnessed consistently at high intensity levels, introduce lower intensity levels and a variety of frequencies.</u>

a) A few trials of each training session should be allowed for experimenting with "new" sounds. For a good audiologic assessment to take place, reliable responses at a variety of frequencies are needed.

b) Continue with this process even after conditioning has been accomplished. Fewer sessions are needed but there should be enough to maintain the response pattern to auditory stimuli at least until the assessment is over.

7. "The box" also may be used strictly for its lights and placed to the side of the child to reinforce localization.

   This may be done by presenting a sound with a noisemaker or "the box" while the child's vision is directed forward. When he turns to the sound, the lights may be turned on flashing to reinforce the head turn. Later, the child may be conditioned to turn his/her head to the perceived sound source in order to receive visual reinforcement which is initiated after the head turn has been completed.

8. Following training without earphones, if an audiometer is available, incorporate earphones into some sessions.

   Present the tones while the headset is on the child and shape the response pattern with "the box". This step is not necessary but will prepare the child well for the audiologic assessment.

These suggestions are a compilation of ideas found to be successful for auditory response conditioning. The box" has been found to be very rewarding for most of our deaf-blind students. Although the process seems simple enough, it may take considerable time to get a good hearing assessment due to the child's readiness for conditioning. "The box," in our opinion, has been the best means available for conditioning multihandicapped children.

In conclusion, suggestions for success in the auditory conditioning of low-functioning children, include the following points:

1. Associate the conditioning sessions with a positive attitude by the staff to maintain a positive experience for the child.

2. Use short conditioning sessions in order to keep frustration and failure at a minimum.

3. Use low frequency stimuli with vibro-tactile information or pair the auditory stimuli with tactile stimulation in order to insure that the child is being stimulated during the conditioning sessions.

4. Use a familiar person with the child.

5. Use control presentations to monitor random responses (ie., false-positives).

6. Be creative in thinking of new reinforcers or variations on original reinforcement paradigms; and

7. be sure to utilize a team approach which gives others participation in the conditioning and testing process.

These suggestions, combined with implementation of the key conditioning elements (waiting posture, stimulus, response, and reinforcer) will increase the success rate for the audiologic assessment of multihandicapped, visually and hearing impaired children.

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WHAT IS MOBILITY?
INDEPENDENCE, CONFIDENCE, SELF-ESTEEM

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I am an Orientation and Mobility Instructor working out of the Vancouver office of the Canadian National Institute for the Blind (CNIB). I have also taught at three agencies in the United States, two in Australia and have helped open a rehabilitation centre in Japan.

In talking today about mobility as independence, confidence and self-esteem, I will try to bring to you some insight and perspective which I have gained concerning blind peoples' mobility, especially blind childrens' mobility.

In the ten years I have been working in this field I have become very positive about several things:

1. Good mobility skills are the blind person's keys to education, socialization, recreation and eventually vocation.

2. The keys to a blind child's mobility are the attitudes and expectations of the parents.

3. Too often the parents' attitudes are negative and their expectations are too low - many times because of lack of active, mobile blind role models.

4. Finally, mobility training for children has been sadly neglected both at home and school.

Mobility is defined simply as a blind person's ability to get from point A to point B safely. Orientation is equally important, and is defined as knowing where one is in relation to points A and B. These definitions are fine for someone who has seen and lost his sight, but mobility training for a child born blind requires a much wider concept. Without good mobility skills, too many blind and visually impaired children have been denied the opportunity to grow into normal adulthood, with the confidence that goes with being able to move freely, and with an understanding of their environment.

To emphasize the importance of mobility to a blind person, please listen to Mike, who was blinded at the age of three and travels with a dog guide. He taped this letter to me 8 years ago while travelling:

(transcript of tape)

"There is nothing more valuable than good mobility, than success. That is -- relatively good mobility. Because when all of a sudden you're able to get around a little better than you did before, or feel a little more confidence, there are doors that open. Gosh, just gorgeous, new experiences, and feelings of self-confidence and self-respect that just open up and blossom and develop, and those things are invaluable. I would say that is more important than anything because that is the key; that is what opens the door up, that's what makes education and sort of the will to live and to experience life to it's fullest. That's what opens it up. And there's more to that than just tapping a cane or crossing streets. Somehow the teacher has got to get inside and strike those cords that make a person motivate himself to get beyond those barriers of fear of various different things."

Another example of mobility providing a source of confidence is a letter from Mike when he was a Master's Degree student in foreign studies in Washington, D.C.

"One thing I really enjoy is the challenge of a new area, and Washington certainly is a challenge in terms of mobility, with all these angled streets, circles and aggressive drivers. I do enjoy getting places, I'm proud of that and I do enjoy it. It's fun moving fast and quickly and confidently around. It's something I do enjoy."

If you remember nothing else from this session, remember those words - I enjoy travelling by myself - I am proud of it.

If any of you as adults lost your sight you would go through a process of loss and grief - shock, denial, emptiness, anger, fear, withdrawal, depression. You would experience one or all of these. Once through the grief process I could almost guarantee you that I could teach you to use a long cane to travel safely anywhere you wanted to go. It would involve learning some simple cane techniques and practice using your remaining senses, but I feel 80% of what I do is help restore confidence. I am there confirming that you are doing well and making correct decisions about when to cross a street. We would work as a team toward the time when you are confident

enough to tackle a route by yourself. It is always a thrill when a blind student does a solo lesson, demonstrating new confidence and increased self esteem.

However, it is most important to have worked through that grief process. Unless it is behind you, mobility lessons are often fruitless. Too often the parents of a blind child are given no help or counselling to get through the grief process of having produced a child born blind. Added to the anger, depression and fear is a tremendous burden of guilt. Too often those feelings of guilt result in over-compensation and over-protection of the blind child - doing everything for the child. Too many times an older parent will ask for mobility lessons for a 30 year old son or daughter who has been overprotected since birth. It is much too late then. Mobility training has to start from day one.

Teaching any of you would be comparatively easy once the grief was dealt with and you were motivated to get on with your life. You have all the concepts, memory and ability to visualize your environment. You could picture in your mind an intersection, a wheelchair ramp, buses, elevators and thousands of other things out there. But none of us can remotely imagine what goes on in the head of a person who has never seen. Think about that - to never have seen a car, a building or a bus. So from day one there has to be a concentration on concepts of right and left, over and under, directionality, body parts, and spatial concepts. Later there is teaching of body language, gestures, good posture, eye contact and social skills. It is usually the mobility instructor who has been trained in this area. Because mobility instruction is one-to-one on the sidewalks and streets it is the mobility instructor who helps teach these concepts and social skills. But starting this training in school is too late. It has to begin with mobility instructors working both with pre-school blind children and most importantly with the parents. Children and parents have to be taught to explore the environment, and not only be taught, but be allowed to explore by touching. Words alone mean nothing to a blind child, the world has to be explored tactually, so he can become informed and talk intelligently about what is out there. It is the parents who make the difference. Parents must seek out the resources and knowledge of professionals, then put them to use - early. Those parents who wait for professionals to do it all, or wait for schools to teach concepts, mobility and living skills, are condemning their blind child to a life of never catching up, always being behind, and always feeling like a lesser person.

I am going to read something concerning mobility instruction

in schools:

> "It is curious that although the literature makes continued references to the significance of orientation and mobility in the lives of visually impaired adults, only at this late date in history are we considering this addition to the general school curriculum, in spite of the fact that it is part of the natural habilitative process of visually impaired children, regardless of where they may attend school." Alonos, 1965, p. 251.

Now, 19 years later, there are still far too many schools that are not putting enough emphasis on mobility training as part of the curriculum for blind students. Mobility is too often put on the "back burner". Only a few years ago at a school for blind children I saw graduating high school seniors pushed and shoved across the stage to get their diplomas. Those youngsters should have been taught to walk independently and with dignity. Every year we mobility instructors are called upon to orient blind students to college campuses. Some of these college students have no mobility skills. We try to teach them routes, but some still choose to manipulate fellow students to guide them, and help perpetuate the myth that blind people are not capable, but are helpless. What is the use of a higher education if a person is unable to leave his home independently?

I want to talk about Rodney, one of my first mobility students, who taught me a great deal about what blind children miss. Rodney was 11 years old, born blind and lived in the hills of Appalachia.

I arrived to teach Rodney mobility skills. His older brother guided Rodney to and from school over a very easy route. Rodney learned long cane techniques very quickly, then the route to school, to the soda fountain, to a friend's house. The townspeople had no idea that blind people could travel independently. One day half the shop-keepers stood and watched as Rodney did a solo route to the soda fountain, taking a shortcut I had shown him over the railroad tracks, and down a steep trail. I was pointing out to them how capable Rodney could be. Unfortunately Rodney's parents never saw his skill in travelling. It was a small town and soon Rodney knew it as well as anyone and I felt his lessons were nearing an end. Then one day we passed a man shoveling dirt into a wheelbarrow. Rodney asked what the noise was. I told him, "a man shoveling dirt." "Oh", he said. Halfway down the block something made me ask Rodney if he know what a shovel was. He did not - I was astounded. I have often thought --- suppose Rodney had said yes? I have since found so many blind

children "fake it". Either no one asks them or for various reasons they say they know about something when they don't.

We returned to the man and asked to see the shovel. The man gave me a funny look because he knew Rodney couldn't see, but I explained Rodney saw with his hands. Rodney examined the shovel and said "Why Ralph, it's just like a great big spoon". That was a pretty good description! I showed him how to use the shovel, he also examined the wheelbarrow and used it, and quickly caught on to how the wheelbarrow saved a lot of steps

I began asking Rodney about other things, and found how much I had taken his knowledge for granted. He knew what the river was because he had waded in it, but didn't know that the roar upstream was caused by the water going over the dam spillway. He had no idea what a dam was. We dammed up a small creek, he felt the water rise, then go over the little spillway we built. We walked to the dam and up a ladder by the spillway so he could get an idea of its size and the force of the water. We began to expand his knowledge of his world. He was like a sponge absorbing information, and finally being allowed to explore with his hands things he had just heard about.

When trying to learn to tie his shoes, he once gave up in frustration and cried "I can't". I told him never to tell me that he couldn't, and motivated by hot dogs and coke he did learn to tie his shoe laces. After countless tries he finally worked up the courage to go down the slide head first. That was a big lesson - he told me that scary things aren't so scary after you once do them. Rodney's social skills, posture, mobility and general knowledge improved.

Since Rodney's parents both worked, I stayed in town one evening so that Rodney and I could demonstrate how well he could travel with his cane. The parents came home tired. No, they would not let Rodney walk to school alone, he might get hurt, his brother could take him. I will never forget how Rodney's shoulders slumped, how it was obvious that his self-esteem "slumped". There was a look of resentment in his brother's eyes, because he was stuck taking care of Rodney. There is no describing how I felt.

I left Rodney 7 years ago. I hope he remembers there is no such word as "can't" and how seemingly difficult things can become easy once you try them. But without practice, cane skills deteriorate, and so does self-confidence. I wonder if sometime in the distant future when Rodney's parents can no longer care for him whether they will ask someone to teach him mobility and living skills. It is the parents who make the difference.

Quite a few miles away, in the next "holler", was Charlene, who is a success story. Charlene was 9, with a vision problem. A greater problem was an ophthalmologist, who had not been out of the hills in 50 years. After an eye examination he bluntly told her parents that Charlene was legally blind and since she was having a difficult time in school she should learn braille. Suddenly the words of a professional had turned a charming little girl with a vision problem into a blind girl with some remaining vision. The parents called me for an evaluation. On my first visit to the school playground it took me some time to locate Charlene, she was keeping up with the other children so well. A simple bar magnifier allowed her to see the large print regular textbooks. A monocular allowed her to see the blackboard.

She had a two wheel bike with training sheels that she rode on the paved school playground. Her parents wondered if they should take the bike away. I advised them not to and I am not sure who had the most fun the first time the training wheels came off and Charlene rode on a two wheel bike, with her father and me on each side, just in case. She did fine, and will continue to grow into a normal adulthood as long as her parents have the attitudes and expectations that she is normal. Parents make the difference.

At this point I would like to talk more about those attitudes and expectations - of parents, teachers and professionals in the field of blindness. Back in the 1960's a man named Scott wrote a book, "The Making of Blind Men". He wrote about services for the blind being either accommodative - taking care of blind people, or restorative - teaching blind people to take care of themselves. In my experience these are the two roads that blind people can travel.

Those who choose one road use services to learn mobility, braille and living skills, get vocational guidance, then go on their way, and the agency does not hear from them again. If those blind persons want to travel, they call a travel agent, if they have a tax problem, they call a tax consultant, etc., just like the rest of us. A recent example was a girl whose third dog guide had died suddenly and she asked for some brush up using a cane. She apologized for having no contact with CNIB for 12 years. That's independence.

Those who choose the second road, use the services of an agency, and use them, and use them and use them. They keep coming back for every available service and for problem solving. They remain very dependent. The lowest functioning people of this second group tend to hang around the agency much of the time. Very often someone drops them off and picks them up at

closing time. They have few contacts with the real world.

And who do the parents of a blind child see when they come into an agency for the first time? The lowest functioning blind people. They see super-dependent blind people, with little confidence, poor mobility and poor social skills. I shudder to think of what those parents and relatives of a blind child think and feel, and of the attitudes and expectations that are formed in those first visits to some agencies. The able blind people are usually blended into the community, living normal lives, going to and from work alone. How can a parent have high expectations unless they can see and meet some able blind people.

The Vancouver office of CNIB has more capable, mobile, independent blind people on the staff than any other agency I have worked with. Also, there are career counsellors working with very able blind young people, so there are some very good role models around the agency.

I believe there should be more capable blind people in blind rehabilitation; those who have lost their sight, and been through the grief process; those born blind who have learned the coping and adaptive skills. These blind people are needed to serve not only as teachers but role models for parents of blind children, blind adults and for the sighted professional staff.

I also wonder how many professionals in some agencies have low expectations. I would like to illustrate staff attitudes at one blind rehabilitation agency in the United States. At this agency, the recreation and education director, herself the parent of a capable blind son, was concerned about staff attitudes and expectations. Because of this concern we organized a two day workshop. At one session the staff was asked to write down the first words they thought of when they heard the word blind. I have kept those slips of paper - 'fear', 'sorry', 'dark', 'depressing', 'bleak', 'helpless', 'poor little me', 'hiding', 'closed off', 'sad', 'alone', 'boring', 'aloneness', 'unfairness', 'problems', 'shuffling along'. How can professionals with such attitudes have high expectations?!

Another example involving staff expectations was in Virginia in 1978. I helped start a camp for blind teen-agers there. One counsellor planned a hard, strenuous hike - and we all <u>knew</u> that all the kids wouldn't make it. One girl was very obese, one fellow was lame, some were very out of shape, and all were visually impaired or blind. So we planned a stop on the trail where we could point out the difficulties ahead and

where anyone who wanted to could take a short alternative way back to camp. When the options were presented to the already tired kids, they all wanted to go on and not one of them quit. We counsellors shrugged and the hike continued. The obese girl needed a lot of help struggling back up the cliff she went over, and the lame bay had a terrible time shinnying across a log over the river - but they all made it. You cannot really describe high self-esteem, but those tired kids had it. They radiated the glow of "I did it". I was rather ashamed I had had such low expectations of them, and in the closing ceremonies told them that we hadn't expected them all to finish the hike. I told them that we counsellors had learned something - don't set low goals for others. We asked for all of them to remember never to allow sighted people to set goals for them - that they will probably always be too low.

I would like to play another tape. Two years after first learning to ski, Mike won three gold medals in the first international blind skiing competitions held in Switzerland. This is a letter he taped to me about expectations:

(Transcript of tape)

> "You know I think back to last year, winning the world cup, everybody saying you're the best blind skier in the world. But it's kind of like a lot of other things in my life; if I accepted sort of the world's or society's rewards on their level of appreciation for excellence and didn't construct my own, I think I'd achieve a lot less, and would have a hell of a lot less fun in the process. You know how people are that don't have any experience with blind people, or even ones that do. You know, you brush your own teeth and they say, "Wow, that's fantastic, you brush your own teeth". Which makes it hard on blind people because you get somebody who maybe doesn't have the support system I did - parents, teachers, good friends, that have given me the ability to do it on my own now. That can just get undermined so easily early on. Some teacher gives a kid an 'A' when he did 'F' or 'C' work and so the kid thinks he did fine, that he's done perfectly, and they let it go at that. Where somebody else is being pushed. They want to do better because people are telling it how it is".

Not only do professional expectations, but parental expectations need to be based upon role models of blind people being capable, independent and integrated into the community. One of my blind role models is Mike, whom I met 10 years ago at a camp for blind people in Northern California. Prior to that I was like the average person who had had no contact with

blindness. But I worked with Mike at that camp. He was the first blind counsellor that the camp had ever hired. One of my first experiences was seeing Mike 50 feet up a fir tree putting up his ham radio antenna. He was a great counsellor, and it was he who made the camp a success, for the first time other blind campers were saying they too might become counsellors. He was a good role model not only for the campers, but for parents and for staff. For ten years Mike and I have been corresponding and his tape letters have been outstanding examples of mobility and independence, such as climbing in the Andes in Peru, visiting the Galapagos Islands, skiing in Switzerland and Austria, and his position in a high technology industry in Silicon Valley in California. If I were to use objectives to describe Mike, "blind" would be way down the list. Words like "bleak", "helpless" or "closed off", used by the staff of that agency certainly do not describe him.

I once asked Mike's mother what her secret way in raising Mike. She said he had brothers and sisters who insisted he carry his share and who treated him as normal, with no pity. It is obvious she didn't overprotect him and I know she must have cringed at the many things he has tried. It's the parents that make the difference. Both professionals and parents have to use more high functioning blind role models for newly blind people and the parents of blind children.

I have seen dramatic changes in attitudes when mobile blind people talk to newly blind individuals who have no confidence or expectations of themselves. Only three weeks ago a boy of 20 or so, who had lost his sight suddenly, was in the office enquiring about mobility instruction. We were in the cafeteria having coffee, I was giving him my mobility pep talk, when a young blind girl in the Job Hunt Club sat down and joined the conversation. She began talking about how frightening it was using the cane at first, but how good she felt when she first crossed a street alone and how now she could get all over town by herself. Her self-esteem shone, and that 10 minute conversation did more for that boy's attitude and expectations than I could have done in a lifetime. He knew I could see - she couldn't.

In 'Self Esteem and Adjusting with Blindness', Dr. Dean Tuttle quotes a man named Kemper, who said, "I was helped most by those who had themselves walked in my path, I was helped most by those who did not feel sorry for me". (2)

WHAT CAN WE DO TO MAKE THINGS BETTER?

Good mobility skills, with the accompanying independence, confidence and self-esteem, are the results of team work between the blind child, the parent and the orientation and mobility instructor. How can we help parents to prepare themselves and their child to be ready to obtain the best mobility instruction?

1. Parental Grieving Process:

Concentrate more on helping parents through the grieving process by organizing support groups of parents who have been through it. Leaders of support groups have traditionally been volunteers. They should be elevated in status and actually hired to offer personal counselling and support, then follow up with telephone networks. It is invaluable to have someone a parent can trust and call upon, knowing the listener experienced the grief and guilt. Parents have to share their concerns and fears with those who have gone through the process.

2. Parental Expectations:

Parental expectations are vitally important for parents and child. Parents need to be consistent individually and together with their expectations. If one parent accepts excuses or poor behavior, the child will take the path of least resistance. If the parents are overprotective, other children will be too, imitating the parents and taking care of the 'poor blind child'. Ted Kennedy, Jr., lost a leg from cancer when he was young. He was asked if, after his loss, his family treated him differently. He answered, "Yes, my dad threw the football at me twice as hard". His brothers still tackled him. It must feel good to be disabled but treated normally instead of being pitied. Every time a parent, child, teacher or friend wants to 'take care of the poor blind child', stop it immediately. Parents have to be educated to blind peoples'capabilities, and then teach this to others.

3. Parental Responsibility:

As I have said throughout my presentation, Parents Make the Difference. Mobility Instructors can be excellent resources but the parents who wait for them to do it all are condemning their child to failure. Parents too often give and give to the child. They must be open to receive from the child. As the child experiences being contributed to, he experiences being loved. But it is when the child experiences contributing to the parents and others that the child experiences being capable, and gains high self-esteem.

4. Parental Training:

Mobility instructors spend a lot of time under blindfold during their training. It helps not only to create greater empathy, but is a practical help later when they are teaching. I believe if parents spent some time under blindfold they could appreciate more the value of sound toys to stimulate movement and could appreciate more how the child must explore tactually. The parents' experience under blindfold could lead to greater insight.

5. Parent's Choice of Role Models for the Child:

Last summer a nine year old girl in Vancouver on holiday met an able young blind man who is an optacon user, and an excellent role model was established. They met accidently because they went to the same church. Parents and professionals must organize a network of role models so that such contacts don't just happen by accident. Role model programs should be an integral part of rehabilitation.

6. Parental Peer Counselling:

After the grief process, continued peer counselling during a blind child's upbringing would be invaluable to promote the sharing of the growing experiences with other parents. Mike's mother is now director of the camp I first worked at, sharing her attitudes with countless counsellors, blind children and their parents. I as a professional can convey to people what blind people can do, but there is a vast difference when a person says, "My child is blind, and he does it".

The professionals are there for the parents to use their expertise, experience and resources, but the parents make the difference.

In conclusion, I would like each of you as parents and professionals to leave here with your attitude of blind children not being visually handicapped, but visually challenged. Remember the tape I played in which a blind man says he enjoys the challenge of a new city. With good mobility skills and the accompanying independence, confidence and self-esteem, the blind child's attitude can also be one of not being visually handicapped but of being visually challenged.

REFERENCES

1) Alonso, L: The Educator's Vital Role in Mobility and Orientation, The New Outlook For The Blind", 1965. 59 (7), 251.

2) Scott, R: The Making of Blind Men. New York, Russell Sage Foundation, 1969.

3) Tuttle, D.W: Self Esteem and Adjusting with Blindness. Springfield, Illinois, Charles C. Thomas, 1984.

TOWARD AN UNDERSTANDING OF LANGUAGE SYMPTOMATOLOGY OF VISUALLY-IMPAIRED CHILDREN

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In recent years language acquisition and use of language by visually impaired children have become topics of increasing interest. This has occurred, to some extent, because of the language delays and so-called deviant language characteristics often noted in the language development of these children. Another impetus for this burgeoning interest is more theoretical in nature; the study of linguistic abilities and disabilities of visually impaired children has the potential of providing information regarding the possible contribution and importance of visual input to the development of linguistic and communicative knowledge by examining the consequences of a lack of such input.

The role of visual input has been emphasized as a major factor in the development of sighted children's early semantic knowledge, in that the relationships between meanings and linguistic forms are thought to be discovered by hearing such forms in the context of what they are referring to (eg., objects, actions, other persons). Much literature on normal language development tends to assume that vision is the primary modality by which children develop understandings of content (meaning) - form (language structure) relationships through the establishment of joint reference with others, although physical action upon objects as well as auditory, tactile, olfactory, and gustatory information also are acknowledged to play an important role. Recent literature, however, challenges the notion that visually impaired children are significantly deficient in semantic development as would be predicted by this position (Landau, 1983). Rather, particular linguistic forms may be assigned specific meanings by visually impaired children that are somewhat idiosyncratic to the child's experience, especially in early stages of language development. Some authors have referred to forms with idiosyncratic meanings as empty or meaningless and have applied the term "verbalism" to the use of so-called meaningless language [see Ayala (1983) for a review of this issue]. Landau noted that semantic distinctions expressed through linguistic forms need to be understood in reference to the visually impaired child's experience with language in the

context of objects, events, and other people in his or her environment. She added that if such experiences are different due to the limited contribution of visual input, the early development of word meanings and language use that varies from conventional meanings and use would be a natural consequence.

In addition to differences in semantic development, another theme that has received much attention is the frequent occurrence of verbal repetition or echolalia in the language of young visually impaired children. It is difficult to say just how prevalent such verbal repetition is; the literature (reviewed by this author) does not provide any estimate. However, clinical experience as well as many published and unpublished reports (Elstner, 1983; Fay, 1973; Prizant and Booziotis, in preparation; Rogow, 1972; Wills, 1979) indicate that echolalic behavior is a common phenomenon. Burlingham (1965) stated that "they use many words which are meaningless to them, in imitation of the sighted" (p. 202). Such repetition has been noted to occur immediately following another's utterance (immediate echolalia) or at a significantly later time (delayed echolalia).

More rigid forms of echolalic behavior have been associated most frequently with children blinded by RLF. A subgroup of RLF children develop behavioral patterns similar enough to behaviors of autistic children that they have been referred to as autistic-like (Keeler, 1958; [illegible]se, 1972). In addition to problems in social interaction, stereotypic behaviors and developmental delays, echolalia is cited as a common characteristic of RLF children and autistic children. However, as mentioned, echolalia has been observed frequently in other children with visual impairment.

Echolalia has been discussed from a variety of perspectives. Nagera and Colonna (1965) included echolalic behavior as an example of verbalism. They described verbalism as a child's use of words in a parroting fashion without having an understanding of their true and complete meaning. Fay (1973) found similarities in the echolalic behavior of a subgroup of visually impaired children when compared to echolalia of children with autism. Wills (1979) discussed verbal repetition of visually impaired children in reference to its possible contribution to communication and the language learning process. In this paper, the previous work of Fay and Wills will be extended in that echolalic behavior of visually impaired children will be considered from the perspective of similar behavior in other children (eg., normal, autistic) as well as in reference to its possible role in social interaction and language learning. The following discussion will draw from our clinical work and research with children

with visual impairment and with autism, and from literature on repetition in the language of non-handicapped children. Thus, a caveat is in order. The following discussion is presented as a stimulus for research, and as a possible explanation for observed echolalic behaviors in visually impaired children, and, therefore, should be construed as tentative pending further research evidence specific to visually impaired children.

Echolalia - Problems of Definition

Schuler (1979) discussed definitional problems in her review of echolalic behavior in a variety of clinical populations. She stated that:

> The term `echolalia' appears to be used loosely, to refer to some not well specified type of repetition of words and phrases. Distinctions as to degree of repetition and comprehension are usually lacking as well as considerations about the intentionality and context sensitivity of the behavior (p. 411).

Problems of definition reflect the fact that echolalia has been used to describe a continuum of verbal behavior, and that delineation of points along the continuum are, in reality, difficult to make. For example, to what extent must a repetition be faithful and indeed, on which dimensions must a repetition be faithful (eg., words, intonation) for it to qualify as echolalic behavior? This problem is compounded by the fact that most echolalic children will demonstrate some rigid reproductions of others' utterances, yet will also introduce segmental (ie., phonemic, lexical) or suprasegmental (ie., intonational) changes in some utterances. More rigid reproductions are typically thought of as more "echolalic-like" while repeated utterances with greater change may be thought of as less "echolalic-like". The latter have been referred to as "mitigated echolalia," and in most cases, probably reflects a greater degree of cognitive-linguistic processing of the original utterance and/or the repeated utterance. Conversely, more rigid reproductions are thought of as reflecting less processing and greater automaticity in the sense of "parroting behavior." In order to understand the significance of verbal repetition of children who frequently demonstrate such behavior, it is important to consider more automatic and rigid reproductions as well as those produced with some change. As definitional issues will certainly not be resolved here, the discussion will shift to the distinctions in echolalic behavior that can be made with greater certainty.

As mentioned, two general types of echolalia have been delineated based upon the temporal relationship between an utterance and a child's subsequent repetition of the utterance. A repetition following immediately after a model utterance has been referred to as immediate echolalia, and such repetition may be the product of some type of short-term echoic memory process (Fay, 1983). In visually impaired children as well as in autistic children (the two groups most frequently assicated with echolalic behavior) immediate echolalia has been shown to vary along with dimensions of degree of comprehension of the echoed utterance as well as the degree of communicative intent underlying its production (Prizant and Booziotis, in preparation; Prizant and Duchan, 1981).

The term delayed echolalia refers to utterances that are memorized and are repeated at a significantly later time, and therefore may involve some type of long-term echoic memory processing. Delayed echolalia may involve repetition of multi-word utterances that are quite sophisticated in linguistic form and may reflect a level of apparent linguistic complexity far beyond that of a child's actual capacity to construct or formulate novel utterances. The production of delayed echolalia may also be associated with particular routines based on specific activities, specific interactions with people, or specific stimuli in the environment. Other terms which have been used to describe delayed echolalia include situational phrases (Will, 1979), prefabricated routines (Krashen and Scarcella, 1978), gestalt language forms (Peters, 1983; Prizant, 1983b) and memorized language chunks (Baltaxe and Simmons, 1977). As with immediate echolalia, delayed echolalia has been shown to vary along the dimensions of comprehension of the repeated utterances as well as communicative intent underlying their production for both visually impaired and autistic children (Prizant and Booziotis, in preparation; Prizant and Rydell, 1984). Furthermore, recent literature suggests that the use of memorized phrases may be far more prevalent in the language of young non-handicapped children than previously suspected (Peters, 1983).

Why Does Echolalia Occur?

Explanations of the occurrence of immediate and delayed echolalia in visually impaired children have focused on two general issues: first, why does a child echo an utterance directed to him or her or, in the case of delayed echolalia, memorize and later repeat utterances; and second, what role, if any, does such immediate and delayed repetition play in linguistic development over time. These questions will be

considered for both immediate and delayed forms of echolalia in visually impaired children and other populations.

Immediate Echolalia

Regarding immediate echolalia, Fay's (1973) discussion of echolalia in blind and autistic children remains one of the most insightful and lucid accounts of this phenomenon. Fay rejected explanations of immediate echolalia as reflecting inattentiveness and a lack of motivation (Milstead, 1972). Rather, he suggested that immediate echolalia is most often associated with a severe language comprehension deficit and its occurrence in blind children relfects "a normal human drive to speak coupled with a severe sensory restriction" (p. 486). For autistic children, he speculated that perceptual, rather than sensory disturbances may be responsible. Fay viewed immediate echolalia in both blind and autistic children as at least "quasi-social" in nature in that a child is attempting to keep the interaction going by repeating other's utterances in lieu of generating novel utterances or responding appropriately non-verbally.

In a recent longitudinal study of a blind child (Prizant and Booziotis, in preparation), we discovered a wider variety of uses of immediate echolalia in early stages of language development based on videotaped analyses. Although most repetitions seemed to serve the social interaction function described by Fay, immediate echolalia was also used to express a variety of intentions including affirming others' utterances (answering), requesting action, and for practicing or rehearsing. In a study of autistic echolalic children (Prizant and Duchan, 1981), echolalia was found to serve both communicative (eg., rehearsal, self-regulatory) functions. In both studies production of echolalia was associated frequently with a lack of comprehension as posited by Fay; however, echolalia was also observed to be used with evidence of some degree of comprehension by the visually impaired and autistic subjects. Clinical obersvations have supported these experimental results.

In summary, immediate echolalia may occur most consistently when a child can't respond appropriately due to a lack of comprehension. However, it may also be the case that immediate repetition is used to serve some communicative functions because a child cannot formulate a response, even if there was some comprehension of the utterance. Intonational changes in repetitions or nonverbal behavior accompanying repetitions often serve to clarify a child's communicative intent. Immediate echolalia has also been found to facilitate linguistic processing and behavioral self-regulation and thus

may serve cognitive functions.

Delayed Echolalia

Wills (1979) examined the use of delayed repetitions in the language of two young blind children whom she followed through their early years of language development. One child was born without eyes and the other child was blind due to retinitis pigmentosa. Wills noted that each child produced novel utterances reflecting early developmental patterns, but each also produced memorized phrases beyond the level of sophistication of their true linguistic abilities. Such delayed repetitions varied as to their appropriateness to the situational context. Wills described the speech of one subject as "often not closely tied to meaning" (p. 110). However, she viewed the use of echolalia and situational phrases as a strategy to participate in social interaction and to communicate intent. She also indicated that echolalia and situational phrases appear to be the children's attempt to master and organize experience in the face of visual impairment.

Two other studies have provided more specific information regarding the use of delayed echolalia by handicapped children. In a videotaped longitudinal study of a young blind girl (Prizant and Booziotis, in preparation) patterns of language structure and use were found to be highly similar to those of Wills' subjects. In a more detailed functional analysis based upon Dore's (1975) categorical system, delayed echolalia was found to be used for the functions of requesting action, labeling, practicing, and commenting. Such utterances were often reproduced in a similar context to which they were originally heard. In a study of delayed echolalia of autistic children (Prizant and Rydell, 1984), fourteen functional categories of delayed echolalia were derived based on videotape analysis. The delayed echoes in each study represented various points along the continua of relevance to the situational context, evidence of comprehension, and evidence of communicative intent.

Pronominal confusion is an additional characteristic of the language of visually impaired children that is cited frequently. Such problems have been described as a misuse of pronouns or pronominal reversal whereby a second or third person pronoun ("you" or "he/she") is used to refer to oneself such as a child requesting a drink by saying "Do you want a drink?" Although explanations of pronominal problems have focused on delays in differentiation of self from other (Santin and Simmons, 1977), clinical observations and literature on other echolalic children (Fay, 1979) suggest

that so-called prenominal reversals can be explained by the use of delayed echolalic patterns. That is, repetition of an utterance directed to a child may include a prenominal form that appears inappropriate when repeated at a later time by the child. It is conceivable that for many occurrences of pronominal misuse, a linguistic explanation may suffice in lieu of a self-concept explanation. Evidence supporting the self-differentiation explanation would be the continued misuse of pronominal forms in utterances that are truly generated or created by a child rather than memorized and repeated at a later time as with delayed echolalia.

In summary, both immediate and delayed echolalia have been found to be used by visually-impaired and autistic children as a device for interacting socially with others, even if at a primitive level. Both forms of echolalia have also been shown to be used to express a variety of communicative intents. It can be argued that such repetitions occur due to a lack of or limited comprehension of the utterances, or to an inability to generate or formulate novel utterances that could serve the same communicative functions. In either case, it appears that visually impaired children use repetition to serve some communicative functions even though they may have limited understanding of such utterances, and limited insight into the internal structure (ie., semantic-syntactic relationships) of the utterances repeated.

More global explanations of the prevalence of echolalic behavior refer back to the second question, what role, if any does such repetition play in linguistic development over time.

The Role of Verbal Repetition in Language Acquisition

To address this question, a more speculative stance must be taken due to a lack of available substantive evidence in the literature. However, in recent years, much discussion on the role of repetition in the language development of normal and other handicapped children has been generated. This literature offers some direction in providing tentative answers for this question. Because this issue has been addressed, albeit infrequently, in the literature on language of visually impaired children, the discussion will begin with this literature and will then shift to relevant literature on language of other children.

Wills (1979) made several references to a possible alternative approach to language acquisition used by her blind subjects. After providing examples of the frequent use of echolalia by one child, she concluded "he was learning his own way, on the basis largely of imitation of words and sentences" (p. 105).

According to Wills, another child "worked through a great deal of what can be termed echolalia and situational phrases in the process of acquiring excellent speech" (p.115). Urwin (1983) speculated that visually impaired children may be demonstrating an "extreme form of a language acquisition strategy" in which "a reliance on phrases acquired wholesale is often coupled with a marked propensity for imitation and/or echolalia" (p. 145).

Our study of language development in a visually impaired subject supports these claims. Over nine months (16 videotaped sessions) we were able to document C's movement from late prelinguistic stages (starting at 1;11) through early multi-word utterances at 2;8). C, whose blindness was caused by RLF, demonstrated functioning at a near age level in all major developmental domains when vision was not a direct factor in the results of the assessments. Therefore, she more closely resembled a normally developing blind child than the subgroup of children with RLF who have been referred to as "autistic-like".

Throughout this period, C's emerging speech and language was characterized by frequent and increasing use of immediate and delayed echolalic forms serving a variety of communicative functions, in addition to forms reflecting early normal developmental patterns (single-word and early multi-word utterances). The specific patterns were as follows: immediate echolalia comprised a high proportion of C's utterances (54%) in the early sessions with a systematic decrease to 5% of her utterances in the latter sessions; delayed repetitions and prefabricated routines (delayed echolalia) increased from 8% to 32% of her total utterances over this period; creative (spontaneously generated) utterances increased from 2% to 31% of her total utterances; and use of non-linguistic vocalizations decreased from 36% to 12% over this period. Although the data has not been calculated, follow-up observations of C for one year beyond the period of the study indicate that immediate echolalia has decreased markedly, while her use of delayed echolalia has increased in frequency and appropriateness to situational contexts. Furthermore, her creative language has increased in proportion to other communative utterances and has become more sophisticated in form. One important finding in the latter sessions of the study and in follow-up data collection is that the emergence of more spontaneous and creative forms appears to be predicted, to some extent, on the segmentation of forms memorized initially as unanalyzed units or verbal routines. Thus, it appears that many of these utterances which comprised an increasingly large portion of her verbal output provided the "raw material" by which C could initially communicate

intent and eventually gain insight into the structure of language through a process of analysis and segmentation.

This account of language acquisition in our visually impaired subject, and Wills' similar findings in her subjects imply that echolalic visually impaired children may indeed be approaching the language acquisition process in a manner that differs qualitatively from most accepted accounts of normal language acquisition (Brown, 1973). However, recent literature on language acquisition of normal children has delineated variations from so-called invariant sequences in language acquisition (Nelson, 1981; Peters, 1983). Furthermore, alternative strategies in language acquisition have been discussed in reference to other handicapped populations whose echolalic behavior has been compared to that of many visually impaired children (Baltaxe and Simmons, 1977; Prizant, 1983b). We will now turn to this literature for the insights it may offer towards an understanding of language symptomatology of many visually impaired children.

Individual Differences in Language Acquisition

The works of Nelson (1981) and Peters (1983) represent the most clearly articulated arguments for the existence of alternative strategies in language acquisition. These authors discussed two types of strategies or styles that may be observed in children who are acquiring language. An analytic style is one in which children in early stages of language development emphasize single words for primarily referential functions and acquire more complex language by combining elements into multi-word utterances based upon the acquisition and application of productive rules. An analytic style is characterized by flexible and generative utterance production with an understanding of the meaning and internal structure of utterances from early on.

In contrast, a gestalt style is one in which children produce unanalyzed language forms with little appreciation of their internal structure or specific meaning, although the utterances may be used somewhat appropriately in communicative interactions. Both Nelson and Peters emphasize that gestalt and analytic styles are not mutually exclusive and that normal children may show elements of each style to varying degrees. For children who demonstrate frequent use of gestalt forms in language acquisition, movement towards the acquisition of a rule-governed linguistic system depends upon analysis of gestalt patterns for linguistic rule induction. However, use of these patterns plays an important role in a child's participation in social interaction. Table 1 provides a summary of gestalt and analytic styles of language

acquisition.

This literature has been applied to an understanding of language acquisition and use of echolalic autistic children (Prizant, 1983b). In reference to autistic children, a distinction was made among three concepts: gestalt forms, a gestalt style of language acquisition, and a gestalt mode of cognitive processing. Gestalt forms and a gestalt style of language acquisition have been discussed above. A gestalt mode of cognitive processing was defined as "one in which events are remembered or retained with relatively little analysis. Linguistic utterances may or may not be part of such events" (Prizant, 1983b, p. 300). In attempting to explain language acquisition and gestalt styles of autistic children, we posited that their cognitive processing style which can be described as gestalt may be responsible. There is clear evidence in the autism literature that autistic children demonstrate cognitive differences and tend to approach the task of retaining information through rote memorization with relatively little analysis. This occurs for linguistic and non-linguistic information. However, there is a lack of such evidence for visually impaired children ("autistic-like" RLF children may be an exception). The question remains: why is echolalic behavior so prevalent in visually impaired children if a particular and somewhat universal cognitive style cannot be attributed to this heterogeneous population

Visual Impairment and Echolalia

To provide possible answers for the relationship between visual impairment and echolalia, we need to consider, as Landau (1983) suggests, the experience of the visually impaired child as he or she is exposed to linguistic input. In other words, is there something unique to a visually impaired child's experience with language and the events in the environment that may be responsible for the acquisition and use of echolalic or gestalt forms.

As indicated earlier, the use of immediate echolalia may indicate a child's inability to comprehend an utterance directed to him or her. Problems in comprehension conceivably may occur due to a child's inability to experience visually the entities and events to which language refers. In other words, without visual support which is so vital to early language comprehension, the visually impaired child may be missing important cues to meaning. Furthermore, the lack of availability of additional gestural and non-verbal cues that caregivers typically use to direct children's attention to referred-to entities (eg., pointing, visual line of regard)

poses additional constraints. a young visually impaired child may not be able to distinguish easily between language for reference as opposed to language for social interaction. Apparently, many caregivers do develop a language style specific to the needs of their visually impaired child such as synchronizing referential comments to a child's experiencing of a referent through touch, taste, or audition (Urwin, 1983). However, a young visually impaired child may not benefit from incidental verbal expressions of others referring to entities or events unless the child is experiencing them through other than visual modalities. This could also contribute to delayed comprehension possibly resulting in a child's efforts to "keep in touch" through repetition.

Another related explanation has to do with visually impaired children's lack of development of non-verbal strategies for initiating interaction and directing others' attention (Mulford, 1983; Rowland, 1983). The work of Rowland (1983) and Urwin (1983) demonstrated that many blind children may develop verbal or vocal strategies in lieu of non-verbal strategies to serve prelinguistic or linguistic functions which are typically comprised of or built upon accompanying non-verbal behaviors. A strategy of immediate repetition may serve a child by providing an audible attention-getter or attention-indicator in lieu of more conventional means for indicating attention or reciprocity. Furthermore, a repetition strategy is likely to encourage a caregiver to continue to interact, and possibly to provide additional cues for the child in attempting to understand the child's intent. A history of such responses may actually encourage echolalic responding.

As mentioned, the frequent use of delayed echolalia and language rituals has been discussed in reference to a possible alternative developmental course of language acquisition for many visually impaired children (Wills, 1979; Urwin, 1983), as well as for autistic children (Prizant, 1983b) and for some non-handicapped children (Nelson, 1981; Peters, 1983). To explain the frequent use of such gestalt language forms, problems of language processing in addition to characteristics of language input may provide some insights.

Peters (1983) discussed the very difficult task that all children face when attempting to learn about language from the language they are exposed to. A basic problem has to do with segmenting the acoustic stream into basic units (words) that correspond to units of meaning in adult language. Even though caregivers simplify language to young children, they still are exposed frequently to multi-word utterances in which individual words may not be identifiable based on perceptual

features alone. Thus, children's extraction of "language units" may not always correspond to adults' units of language and in some cases a child's extracted unit may be a multi-word utterance or even two utterances in succession. It seems that when such verbal routines are heard regularly in recurring interactions or are produced by others with significant emotive intoning, children are likely to process them as unanalyzed wholes, and may reproduce them later as heard. In some cases, children may be focusing more on intonational characteristics rather than the words in such utterances as evidenced by the often faithful reproduction of intonation co-occurring with poor or unintelligible articulation of segmentals. Memorization of multi-word units is less likely to occur when a child is able to segment language that he or she is exposed to. In addition to auditory perceptual cues which may be used by caregivers (eg., hesitation, pause, contrastive stress), non-verbal and gestural cues are often used which may aid a child in noting how language units may correspond to dynamic events. For example, not only does referential labeling often occur with pointing, but caregivers will often label actions as they are being performed (eg., open, pick up). Without visual cues which provide some additional support for linguistic segmentation, a conceivable consequence could be the acquisition of many unanalyzed forms.

A final explanation would have us examine language direction to children that is used for primarily social, rather than referential purposes. Nelson (1981) indicated that "social control language" tends to be more ritualized and less easily segmentable (eg., "stop it," "give it to me"). Language used in social games and interactive rituals tends to have the same qualities. It is conceivable that caregivers of visually impaired children would be more likely to engage in social language embedded in highly ritualized interactions rather than referential language, especially in early stages of language acquisition. Furthermore, social control language may play a greater role in caregivers' attempts to signal potential hazards to a visually impaired child as he or she attempts to explore the environment. This was clearly the case in our longitudinal study of C (Prizant and Booziotis, in preparation) and similar patterns have been pointed out by others (Urwin, 1983). We also found that the great majority of C's creative utterances were referential while her memorized verbal routines tended to be more social in nature and were comprised of reprimands, utterances from frequently recurring interactive routines, and verbal warnings about hazards in the environment.

Thus, the prevalence of gestalt forms in the language of visually impaired children may be precipitated by a variety of

factors including:

1. Normal variation noted in acquisition styles across all children acquiring language.

2. Delayed development of language comprehension with a relatively more sophisticated rote memory for speech allowing for short-term or long-term retention of utterances associated with situational features.

3. Difficulties in segmenting language due to unavailability of visual cues marking segments of dynamic events, and

4. Characteristics of language input to visually impaired children.

Clearly, some of these factors may put visually impaired children at greater "risk" for development of a gestalt language acquisition style, however, it would be inappropriate and inaccurate to conclude that blindness causes echolalia and a gestalt acquisition style. This statement can be refuted easily by the identification of visually impaired children who do not demonstrate gestalt forms in their speech. Rather, it may be more fruitful to identify which factors are more closely associated with echolalia and a gestalt style in visually impaired children who demonstrate such symptomatology as opposed to those who do not. It is only through such analyses that more definitive links between the experience of visually impaired children and the occurrence of echolalia and gestalt styles of language acquisition can be made.

Conclusions and Further Questions

The intended purpose of this paper was to raise some theoretical issues regarding the often cited symptomatology of echolalia in the language of visually impaired children. By design, the discussion has remained tentative and somewhat general, largely due to the paucity of literature on the subject. Some obvious difficulties with the discussion include the lack of a clear differentiation among subgroups of visually impaired children based on factors such as etiological conditions, cognitive level, extent of visual impairment, the need for additional research support for some of the claims made, and the need for very basic information such as how prevalent gestalt language symptomatology is. Further, reliance on information from normal and other handicapped children may not be the most valid approach for understanding behavior of visually impaired children.

Another question that justifiably may be raised is the

practical significance of such information for caregivers and professionals who live and work with visually impaired children. Again, clinical experience and literature on other populations must provide a tentative answer. Peters (1983) has suggested that children who demonstrate a gestalt style of acquisition may have greater difficulty "breaking into" language and acquiring the use of a generative, flexible means of communication. This would imply that caregivers and professionals need to develop interactive strategies to help visually impaired children to segment and relate meaning to language they hear. Adults' appropriate language adjustments and experientally based language are obvious priorities and are fundamentals of most programs for visually impaired children.

Another problem often precipitated by the presence of gestalt language forms is that they may lead to an overestimation of a child's true language level resulting in levels of attempted linguistic interaction far too sophisticated for a child. For example, efforts may be undertaken to have a child at a one or two word language level memorize and use grammatically complete forms because he or she may produce gestalt forms of greater apparent linguistic complexity. Assessment of and intervention for children with gestalt language symptomatology needs to be based on a thorough understanding of what at first may seem to be a very confusing linguistic picture [see Prizant 1983a) for further discussion of assessment and intervention issues]. However, greater understanding of such behavior should lead to the development of strategies to help visually impaired children use the language they have acquired most effectively, and to eventually develop a flexible and generative communicative system.

REFERENCES

1) Ayala, M: Verbalism in the Language of Visually Impaired Impaired Children. Unpublished doctoral dissertation Southern Illinois University. (1983).

2) Baltaxe, C.A.M., and Simmons, J.Q: Bedtime soliloquies and linguistic competence in autism. Journal of Speech and Hearing Disorders. (1977). 42, 376-393.

3) Brown, R: A First Language. Cambridge, MA: Harvard University Press. (1973).

4) Burlingham, D: Some problems of ego development in blind children. Psychoanalytic Study of the Child. (1965) 20, 194-208.

5) Chase, J.B: Retrolental Fibroplasia and Autistic Symptomatology. New York: American Foundation for the Blind. (1972).

6) Dore, J: Holophrases, speech acts, and language universals. Journal of Child Language, 2. (1975) 21-40.

7) Elstner, W: Abnormalities in the verbal communication of visually impaired children. In: A. Mills (Ed.), Language Acquisition in the Blind Child - Normal and Deficient. San Diego: College-Hill Press. (1983).

8) Fay, W.H: On the echolalia of the blind and of the autistic child. Journal of Speech and Hearing Disorders, (1973) 38, 478-489.

9) Fay, W.H: Verbal memory systems and the autistic child. In: B.M. Prizant (Ed.), Seminars in Speech and Language. (1983) 4, 17-26.

10) Keeler, W.R: Autistic patterns and defective communication in blind children with retrolental fibroplasia. In: P.H. Hoch and J. Zubin (Eds.), Psychopathology of Communication. New York: Grune & Stratton. (1958).

11) Krashen, S., and Scarcella, R: On routines and patterns in language acquisition and performance. Language Learning. (1978) 28, 283-300.

12) Landau, B: Blind children's language is not "meaninglass." In: A. Mills (Ed.), Language Acquisition in the Blind Child - Normal and Deficient. San Diego: College-Hill Press. (1983).

13) Milstead, J.R: Modification of echolalic speech in a blind, behaviorally deficient child using parental contingency management. Journal of Communication Disorders. (1972) 5, 275-279.

14) Mulford, R: Referential development in blind children. In: A. Mills (Ed.), Language Acquisition in the Blind Child - Normal and Deficient. San Diego: College-Hill Press. (1983).

15) Nagera, H. and Colonna, A: Aspects of the contribution of sight to ego and drive development: A comparison of the development of some blind and sighted children. Psychoanalytic Study of the Child. (1965) 20. 267-287..

16) Nelson, K: Individual differences in language development: Implications for development and language. Developmental Psychology. (1981) 2, 170-187. .

17) Peters, A: The Units of Language Acquisition. New York: Cambridge University Press. (1983).

18) Prizant, B.M., and Duchan, J.F: The functions of immediate echolalia in autistic children. Journal of Speech and Hearing Disorders. (1981) 46. 241-249. .

19) Prizant, B.M: Echolalia in autism: Assessment and Intervention. Seminars in Speech and Language. (1983a) 4, 63-77. .

20) Prizant, B.M: Language acquisition and communicative behavior in autism: Toward an understanding of the "whole" of it. Journal of Speech and Hearing Disorders. (1983b) 48, 296-307. .

21) Prizant, B.M., and Booziotis, K: Language acquisition strategies of a blind child. (in preparation).

22) Prizant, B.M., and Rydell, P: An analysis of the functions of delayed echolalia in autistic children. Journal of Speech and Hearing Research. 27, 183-192.

23) Rogow, S.M: Language acquisition and the blind retarded child: A study of impaired communication. Education of the Visually Handicapped. (1972) pp. 36-40. .

24) Rowland, C: Patterns of interaction between three blind infants and their mothers. In A. Mills (Ed.), Language Acquisition in the Blind Child - Normal and Deficient. San Diego, College Hill Press. (1983).

25) Santin, M.A., and Simmons, M: Problems in the construction of reality of congentially blind children. Journal of Visual Impairment and Blindness. (1977) December, 425-429 .

26) Schuler, A.L: Ecolalia: Issues and clinical applications. Journal of Speech and Hearing Disorders. (1979) 44, 411-434.

27) Urwin, C: Dialogue and cognitive functioning in the early language development of three blind children. In: A. Mills (Ed.), Language Acquisition in the Blind Child - Normal and Deficient. San Diego: College-Hill Press. (1983).

28) Wills, D.M: Early speech development in blind children. Psychoanalytic Study of the Child. 34, 85-117. (1979).

TABLE 1 - Analytic and Gestalt Modes of Language Acquisition and Use

ANALYTIC MODE	GESTALT MODE
1. Basic units of language are single words.	1. Basic units of language may be words, multiword utterances, phrases, and/or clauses and all possibilities may co-occur as units during one period of time.
2. Early language acquisition involves movement from single words to two and three word utterances encoding early semantic functions and relations.	2. Early language acquisition involves acquisition of multiword units "functioning" as single words. May involve utterances which appear grammatically sophisticated.
3. Further growth in language is achieved through acquisition of grammatical morphemes and functors allowing for noun phrase and verb phrase elaboration.	3. Further growth in language involves analysis and segmentation of unanalyzed chunks into constituent components, and/or movement to an analytic mode.
4. Language is productive and generative from early stages of acquisition with rule induction allowing for increased complexity.	4. Language is relatively inflexible in early stages with limited generativity. Increased complexity is achieved through recombinations of "prefabricated patterns," and further movement to an analytic mode.
5. Language use is generalized to relevant objects and events after short period of situationally specific usage.	5. Language use may remain specific to situational contexts for extended periods.
6. Analytic processors may be more focused on internal structure (semantic and/or grammatical relationships) and referential use of utterances (e.g. Dore's "word babies").	6. Gestalt processors may be more focused on intonation and use of language in the structure of social interaction (e.g. "intonation babies").

ADAPTING THE ENVIRONMENT FOR THE VISUALLY IMPAIRED STUDENT: PRACTICAL METHODS AND MATERIALS TO ENHANCE THE USE OF LOW VISION

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When it is your job (as an itinerant or resource teacher) to support the regular education teacher, who is serving a visually impaired child, it often seems that each year begins in an atmosphere of crisis. Any teacher who discovers, three days before school begins, that her classroom of thirty-three children will include a "blind" student has reason for concern. And that anxiety springs from the best motives; most instructors are well aware that the average student receives about three minutes per day of individual attention. How, then, is a blind or partially sighted child to be adequately instructed?

Nothing is more important, I feel, than answering this question well. The regular teacher must know which subjects require special books or materials; when her usual teaching methods do or do not need adapting for the visually impaired child; how she can arrange her teaching, the room or media used to include this special child. She also needs to know in what ways she can depend on you. After all, you are only in the classroom a small portion of the total teaching day. This initial consultative work will set the climate for instruction for the school year.

On my first visit with the classroom teacher, I describe the nature of my support services to her - ie: I will be assessing the child, with the goal of outlining all adaptations for vision that will help the child in the school program. To communicate these adaptations, I complete the "vision summary sheet" (see Appendix A,) which discusses where the child should sit, the type of print used for various subject matters, fatigue factors, and so forth. Only after I have completed this consultative/evaluative work for the regular teacher will I designate the scope and nature of other direct services to the child.

In addition, I discuss with the teacher the four basic factors I evaluate to determine how to adapt the environment of the classroom for the child with low vision. These factors, and a

description of how I assess them follows:

1. How appropriate is the work space?

2. Are there any color-contrast problems?

3. How effective is the lighting? Are there any glare factors?

4. What adaptations can improve reading instructions?

HOW APPROPRIATE IS HIS WORK SPACE?

What do you do when your visually handicapped student has been seated at the front of the room or in the corner, looking either extremely conspicuous or vaguely ostracized? Generally, a student is thus seated because of the best intentions. And, to be fair, the child who needs an extra light plug for a lamp, or additional space for large print books, or to peer at the blackboard from close up, may need to be seated differentially.

There is no pat formula to solve the problem of working space. If the only way the child can read is with his study lamp, he may have to be seated next to the outlet. If the need for the lamp is marginal, social factors (being seated the same as the other children,) may be paramount. As in most decisions of this nature, common sense must rule: the student should be seated as much like classmates as possible.

One compromise that has been effective has been to suggest that the child have two work spaces: his regular desk and an additional "study centre" with his lamp, special books, magnifier, and so forth. Thus, the child completes some tasks with classmates, others at his special area.

Since space is such a premium, I make the "study centre" more practicable by providing aids that can be used by ALL the students. For example, if it fits with classroom needs, I can provide a "magnifier station," with an illuminated bar magnifier for use in dictionary work, or a "listening centre" with tape recorder and tapes. Thus, my student is only one of many using the station, and the teacher has the bonus of attractive gadgets for use by all.

If I had a choice, (and I rarely do,) I would prefer to have my student seated at a flat table rather than a desk, even though the angle of the desk top is visually better for the child. I can't fit or maintain aids like a lamp or bookstand onto the desk. They slide off or cause enormous clutter.

And speaking of clutter, many teachers of visually impaired children claim to be able to identify the work space of their student, without ever having met the child, by the amount of "mess" that surrounds the desk. Personal organization, including the ability to organize books, papers and assignments in a coherent fashion is an important skill.

To help the child, teachers have glued cigar boxes to table tops, in which the student can place his glasses, magnifiers or pencils and crayons for ease in retrieval. In some cases, special desk pockets have been used to organize paperwork. For example, one sturdy pocket is attached to the left side of the desk for unused paper, a second in the front of the desk for uncompleted assignments; a third to the right for completed work. Another successful idea has been the travelling "briefcase" composed of four accordian style folders, taped together in a graduated manner, one just below the opening of the folder above it. Each folder is labeled in large print or braille by subject matter.

Whether the student is seated at a desk or a table, he is likely to need to be near the teacher, since many adapted materials need to be handed to him easily. Usually, by sitting near a flip chart, the child can use it well, since the print is traditionally written in large letters.

For the overhead projector, there are several options. The student can sit next to the projector and use the lighted table, or the teacher can provide the student with a xerox of the acetate sheet.

The teacher has several choices about adapting the blackboard for the visually impaired student. She can seat him near it, if his vision is good enough to see at that distance, give him permission to walk up to the board as necessary, or write out the information for him to use at his desk. If I had to generalize about the best place to seat most children with low vision, it would be front-centre in the class. Interestingly enough, and with or without my help, it often happens that this is where the regular classroom teacher seats the child, through trial and error. Obviously, great minds think alike.

An easily overlooked, but important factor in relation to seating is to be sure that the child's chair is the right height for his desk or table. Posture is already a critical issue for the child; sitting at a table that reaches his chin won't help any.

Speaking of desks and tables leads naturally to the next factor I check in the classroom environment:

ARE THERE ANY COLOR CONTRAST PROBLEMS?

It has been amply documented that it is much easier to see objects with crisp color contrast than to distinguish objects of slightly differing hues. In many classrooms, this basic optical principle goes ignored. Often, we use light colored desks and tables, against light colored floors and walls. While the student with normal sight adapts easily, the lack of contrast can create a wide variety of problems for the child with low vision. Beige chairs may "disappear" into the beige floor; white paper may blend into the light wood of the desk, making it difficult to know where the edge of the paper or book is; mobility is more difficult when objects do not stand out clearly from the background.

To prevent this problem, be sensitive to work surfaces and adjacent areas. A piece of black construction paper, cut slightly larger than the page of the book, and placed behind the page, provides immediate contrast (it also cuts the amount of reflectance from the page.)

To provide contrast betweeen the desk and work materials, a typing mat (made of hard rubber so the child can write on it, such as RubberMaid manufactures,) can be placed on the desk. In a pinch, black construction paper will do. Recently, we found some floor mats in an auto store for under $2.00 each that are perfect for a desk. The obverse side is smooth, black rubber and the mats do not slip when the child uses his pencil. The benefits of non-slip surface for handwriting practice is self-evident, particularly if a child has any palsy or lack of fine motor coordination.

Take a look at the contrast between the child's chair and the floor, as well. After a classroom teacher confided to me that my first grader (who had very little vision,) had fallen twice when trying to sit down, I outlined his beige chair with black masking tape. Naturally, he retaped a large "X" on the chair and played "bombs away" for a while. But he also did not fall again.

For pre-school teachers, another seating arrangement that should be inspected for color contrast problems may be the toilet. A white bowl against light tiled flooring may present difficulties, particularly for little boys, whose aim is uncertain. Raise the lid and tape black electrician's tape around the bowl.

Take a look, as well, at any aid the child is using, such as a

magnifier. Simply place a piece of contrasting tape on the handle, to make it easy to locate.

In one case, I had a complaint from the regular teacher that the visually impaired child was taking too long to change activities, such as putting away work, getting her coat and lining up for recess.

I placed colored, reflecting tape on difficult to see areas, such as the coat hooks, door knobs and individual cubbyholes in the room, as well as her lunch pail, which was similar to many others. I supplied the classroom with a large yellow all-purpose ball, in preference to the brown one in use, so my student could find and retrieve it more quickly. I also placed reflecting tape down the four steps leading to the playground, (there was no railing,) which speeded the child to recess. And finally, a large yellow comb in her brown purse, to replace the brown comb she ordinarily used, saved a great deal of time before and after lunch.

All of these ideas enhance the use of low vision by providing for good color contrast, and are duly recorded on the "summary sheet" referred to previously for the classroom teacher. We know that many color contrast problems can be solved by the proper use of lighting, which brings us to the third factor:

HOW EFFECTIVE IS THE LIGHTING? ARE THERE ANY GLARE FACTORS?

A proper level of illumination is often the most effective non-prescription low vision aid a child can use. This means either increasing the level of illumination, or decreasing it, especially through the control of glare.

While it is difficult to generalize - each child will react individually to lighting - it is often true that children with optic atrophy, retinitis pigmentosa and retrolental fibroplasia (RLF,) will do better with high levels of illumination. This is often true of students with cortical blindness, perhaps because they often have more peripheral than central vision, and strong lighting stimulates the rods which are packed more densely in the periphery of the retina.

Children with albinism, glaucoma and central cataract often need less, or more controlled lighting. Bright light bouncing off cataracts has been likened to glare off a dirty car windshield, and the eye with glaucoma may have a cloudy, gray cornea so that light scatters through it. Albinism, of course, is the absence of pigment in skin, hair and eyes, which invariably leads to photophobia, or extreme sensitivity to light.

If the child needs more intense illumination, he should use a hooded lamp, so that the light is well diffused. It is useful to train the child to use a rheostat on the lamp (a control for increasing/decreasing the intensity of the light,) whenever possible. The lamp should be positioned on the side of the BETTER eye, so that light rays bounce into the eye with poorer vision. Because the standard table lamp is not always convenient in the classroom, an alternative is to purchase a lamp with a moveable stand, with wheels, and a 48" arm that is easily adjustable. These function well in the workshop or music room where the student cannot work at a standard desk.

As long as schools continue to use fluorescent lights - which is poor lighting for all children - the individual lamp is an extremely important aid.

Given the average illumination level in a classroom, the need for light control generally means controlling glare. For example, I have found that most aphakic children - those with cataracts removed - function well in average lighting. But given any level of glare, they have problems. This may be because the child with a cataract removed has lost the lens of the eye. The lens naturally contains a yellow pigment, by which the eye screens glare. Without this pigment, overly bright light may cause discomfort.

Some youngsters need glasses which are tinted to darken in the sun, or to use clip-on sunshades. Children who won't hear of other devices may acquiesce to a baseball cap; the visor is having a resurgence of popularity since the Los Angeles Summer Olympics.

Within the classroom, I check at different times of day for glare. The most difficult area to correct is often sunshine through classroom windows, which can make the student's desk or the blackboard unusable at certain times of the day. If my student cannot be moved out of the glare, I may request permission to cover a portion of the offending window with black matting.

I check the student's work surface to be sure it is glare-free. Too much light on a white page of print can be controlled by using a typoscope, if necessary. This is a device that looks like a black book marker, with the width of three lines of print cut out of the centre. It vastly reduced light, and thus glare, on a page and is easily constructed.

If the teacher uses television in the classroom, a color set is much preferable for low vision. It provides much better

contrast; details are more easily seen. It is especially important to leave a light on in the room, since without a light source, any television looks as if the picture is oscillating. Children with nystagmus, for example, will "oscillate" right along with the television.

Whether the child works well with more or less illumination, the control of glare is equally important. It is an irritant for anyone, especially when working on near vision tasks like reading, which is the next factor I evaluate.

WHAT ADAPTATIONS CAN IMPROVE READING INSTRUCTION?

What could be more important to the student's long term progress than reading? Here I have the opportunity to share my special perspective with the regular teacher, in terms of vision.

Visual Fatigue:

The student may be expending a great deal more physical effort in completing his work than the normal sighted child. He may need to twist his head to use his best eye, or have to bend over to get very close to his work. It may take him more time to complete a task for mechanical, not intellectual reasons. I report any necessary time adjustments to the teacher. Also, his eye condition may be such that his eyes need a rest due to visual fatigue after a period of close concentration. Photophobia - extreme light sensitivity - may also lead to fatigue.

I urge the classroom teacher to allow the child to participate in reading instruction as early in the day as is practicable, when the child is rested, and before fatigue factors intrude. In some cases, the afternoons need to be given over to less visually demanding/fatiguing tasks for the student with low vision.

Lighting Control:

I make the teacher aware of any lighting adaptations, such as lamps, typoscopes or visors worn indoors. Since the normal classroom rule is "no hats worn indoors," the teacher needs to know why there may need to be an exception.

Reading Distance:

The student should be encouraged to read at ANY confortable distance. This may literally place the child's nose on the page; it will not affect his eyes, but may very much affect

his neck and thus I may be experimenting with reading stands of various types.

No one likes reading stands much. Children find them too conspicuous; teachers find them too obtrusive, and I hate arguments. Nevertheless, after several students have needed neck braces, I find them worth trying. Any sturdy stand will do, provided it has a good shelf to hold the material and is not overly wide or tall, and will not crash to the floor when a large print book is placed on it. Here are several adaptations to make them easier to use:

-teach the child to use a rubber mat under the stand, so it does not slide around the table or desk.

-rubber bands placed on the stand, to hold the book open, make it difficult to turn the pages. An adaptation, suggested by one teacher, is to attach two elastic bands to the top of the stand, about four inches apart. A plastic eyelet is secured to the bottom of each band, which can be hooked into a screw hook placed on the lip of the stand. The band can be "unhooked" to turn the page, and frees the child's hands to use other reading aids if necessary.

-for smaller books, squeeze clips will keep the book flat on the reading stand. It's suggested they be painted black, to avoid glare under the reading lamp; clips are available from any stationary store.

-since a reading stand raises material higher than it would be with it lying flat on a table, check to be sure the table is low enough, so that materials aren't "too" high for your student.

Materials and Media:

I find it very useful to explain to the classroom teacher how I arrive at a choice of print for our mutual students.

I explain that normal reading distance in all but the youngest readers is about 40 cm. (16 inches). Regular print size is 1M print; larger print is the 2M print size. By making a fraction consisting of reading distance/print size, I can estimate what a child will use. Thus, for a child to use regular print, he needs vision of about 20/50 or better. (40 cm/ 1.00 M) = 40/100 = 20/50 Snellen equivalent).

It takes about 20/100 vision to read large print at a normal distance of 16 inches. (40/200 = 20/100).

Therefore, a child with 20/200 vision will read large print very successfully. He will simply bring it twice as close - that is to say, he will read at 20 cm (8 inches) rather than at 40 cm (16 inches). Now, I am personally very fond of this distance - 20 cm or 8 inches. You see, most pencils are about 7 inches long. There is a great functional advantage to the child in being able to get his pencil under his nose when doing a workbook. Takes much less time.

Most primers are large print. Often, a child with 20/200 vision or better will need no adaptation for the reader through Kindergarten, 1st and 2nd grade. Media changes enough during 3rd grade to require a new evaluation.

If the child is using a consumable workbook in these early grades, he can often use it without adaptations. If the teacher is making ditto masters from the workbook, you must adapt. Get the child his own workbook to use as a consumable.

If the teacher is creating her own dittos, ask her to clip a sheet of black carbon paper and a sheet of plain white paper to the back of her ditto master, when making the original. If she will press a little harder than usual, she has a good black and white copy for the visually impaired student.

Math books and workbooks are different, I find, from the reading materials, for example, I have had many youngsters who needed large print for readers but could use regular print for math. There are, perhaps, fewer variables in these books, and spacing and contrast in math books is carefully controlled.

Tracking Skills:

Normally sighted youngsters, learning to read, generally have some problems learning to track well. They may lose their places within a line of print, skip words, or even skip whole lines of print. My observation of children with low vision is that they have a most difficult time with anything requiring spatial abilities, such as tracking print. Therefore, I specifically assess this for the classroom teacher. (See Appendix B for my assessment tool.)

I work with the child to teach him how to best hold the book. Perhaps he should use eccentric viewing to utilize a preferred eye with better vision. He may need a bookstand or more color contrast in his work area. I check to be sure he knows where to begin reading on a page, where to look for page numbers (and whether he can see them, even in a large print book), how to turn a page and how to get from the end of one line to the beginning of another.

I may encourage the beginning reader to use finger pointing, which is an anathema to many fine primary teachers. I explain that since the beginning reader is using an average of 2.5 eye movements per WORD, (these are termed "saccadics,") moving the finger from word to word is not slowing down the child's reading. I explain that many children with low vision, particularly those with eye muscle problems, need a technique to focus the eyes onto each word. The finger acts as a kinesthetic cue to the eyes, assisting the child in controlling the tracking from word to word.

If the child is having a VERY difficult time, and it is my sense that he is somehow "overwhelmed" by the amount of symbols on a page, I may teach him to use both finger pointing and a black book marker above the line of print. (Generally, I feel a book marker should be placed above, not below, the line of print being read, so that it does not intrude on the natural flow from the end of one line of print to the beginning of the next line.) The typoscope, referred to previously, I use as a light control device, not as a book marker.

Throughout my discussion of how and why I evaluate the classroom environment for the child with low vision, I have emphasized constant formal and informal communication with the classroom teacher. Since I am, after all, only support personnel to that teacher, who is serving my student in the mainstream, the quality of his year will depend on the climate created by that teacher.

Beyond this support to the mainstream is my individual program with the visually impaired student I serve. This program will be as varied as the child's needs, but it will always include one important aspect of learning. For a visual adaptation to be realistic, it must be one that the child understands, can duplicate and will use.

Adaptations are only useful if the child can do them absolutely independently. It is the student with low vision who must understand how to adapt that environment, and that implies a great deal. It means, among other things, that the student has specific information on his own visual condition and functioning. It implies that he will have the confidence to request, if not demand, certain reasonable changes in the school program, so he can perform most fully.

It does not imply that we are discussing only older-aged students. I have found, to my vast and continuing pleasure, that it is often the four or five year old who shows

consummate common sense in adjusting to low vision.

When little Wendy was in Kindergarten, she was cornered on the school yard by three little boys who wanted to know, without any cruelty intended, why her eyes looked so big behind her aphakic lenses. "Well," said the pixie, whose red hair advertised her personality, "all it means is that instead of being pretty with little eyes, I'm pretty with big eyes." The boys - and I - nodded in total agreement.

APPENDIX A.
SUMMARY SHEETS FOR VISUAL ADAPTATIONS

Functional Vision Checklists: Summary Sheet Date _____
Student _____ Age___ Grade_____School_____
Vision Teacher _____Contact Phone _____Room_____

Physical Information
Nature of eye condition (describe in simple terms) _____
_____
Educational implications of eye condition _____
_____
Glasses prescribed _____ To be worn _____
Describe prescription (bifocal, aphakic, contact)_____
_____
Acuity - Near Vision _____ Field _____
Acuity - Far Vision _____ Color Vision _____
Preferred eye _____ Child is/is not binocular _____
Preferred field of view _____ Best gaze posture, if any _____
Photophobia_____Sunshade prescribed _____
Classroom Modifications: distance vision. Child can use -
overhead projectors _____ flipcharts _____
filmstrips _____ flashcards _____
television _____ wall clock _____
Blackboard: child should be seated:
in front row ___ front-right_____front-left ____other_____
Distance aids used _____
_____
Time adjustments (such as extra time to copy from blackboard__
_____
Classroom Modifications: near tasks
A. Reading:
Optimum reading time _____
Child prefers to improve visual functioning by _____
_____
Child's grade level when reading print _____
Print size: _____ Reading _____Mathematics
_____ Activity books _____ditto papers
_____ Dictionary _____others
Adaptations of reading materials: _____
_____

B. Near Vision aids:
Use of optical aids _____
_____
Reading stand _____Marking pen _____ Writing paper _____
Typoscope/marker_____ditto filters _____
Closed Circuit Television (CCTV):
_____best magnification _____ polarity _____ reading distance.
Special lighting required _____
Auditory (listening) program _____
Child's grade level for auditory reading: _____
Type of classwork to be read by ear _____
_____
Equipment Adaptations for Classes: will the student need special adaptations in: cooking _____ sewing_____ shop _____ laboratory _____ Physical education ____
_____
Testing Situations
Modifications required (time and materials)_____
_____
Travel Skills
Oriented to:_____ school _____ Bus _____ community.
Can travel independently _____ Adaptations for independent Travel _____
_____
Time adjustments _____
Additional notes _____
_____
_____

APPENDIX B
NEAR VISION: TRACKING SKILLS ASSESSMENT

RECORDING SHEET: VISION SCREENING

NEAR VISION

Tracking Skills	YES	NO	COMMENTS
When reading orally, does the child			
a. hold book appropriately to maximize field.			
b. know how to turn pages			
c. understand page numbering			
d. know where to begin reading on a page.			
e. track from word to word			
f. Track with:			
1. head			
2. finger			
3. one eye			
4. both eyes			
g. frequently lose his place within a line of print			
h. have difficulties reading from the end of one line to the beginning of the next.			
i. frequently omit small words - "a, to, for" - or prefixes, suffixes of words.			
j. omit words in the same general area on the page.			
k. skip lines on print			
l. misalign digits in number columns.			
m. mispronounce similar words.			
n. evidence reduced comprehension as reading continues.			
o. read at "average" speed for grade level.			
p. use book markers or typoscopes			

Other comments _____

_____

NEUROVISUAL ADAPTATIONS TO SUBNORMAL VISION IN CHILDREN

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The care of children with subnormal vision is a challenging and often time consuming part of any pediatric opththalmic practice. Perhaps no other problem in pediatric ophthalmology is as challenging to the skills of a physician. Regrettably, the underlying metabolic and structural nature of most of the common causes of congenital blindness in children are still a long way from precise definition. Definitive therapy for most of these conditions is rarely possible. Thus, the grief experienced by parents of a child with subnormal vision is a long term problem that demands support from all involved in the care of these children. Nonetheless, those of us involved in the evaluation and care of children with subnormal vision are privileged to observe and learn from the various physiologic ways in which these children adapt themselves to their visual handicaps.

The phenomenology of neurovisual adaptations to subnormal vision in children is not only intellectually interesting, but of real practical importance. Some of these adaptations are seen as mannerisms or behaviorisms of no inherent value, by teachers, rehabilitation personnel, and physicians. In this paper I hope to give an overview of the physiologic mechanisms by which children routinely attempt to enhance their poor vision.

The most obvious adaptation to subnormal vision seen in children is the shortening of the focal distance of objects of interest. This often alarms parents when they realize that their visually handicapped child may inspect small items only a few centimeters from his eyes. Nevertheless, the advantage of shortening the focal distance in the child with subnormal vision is essential to understand for a number of reasons. One of the primary reasons why a child with poor vision may view objects of interest at a very short focal distance is that by doing so he obtains magnification. Most of you will recall that by the increase in accommodative response of an eye one can add to the magnification supplied

by a simple plus magnifier. With a 25 cm. reference distance, the magnification given by the eyes' accommodation is in a ratio of 4 diopters to 1 magnification unit, the same as that provided by a lens. Thus, the magnification due to accommodation adds directly to that due to the lens itself (1).

An important clinical implication of the above is that a child of 10 years of age or less with poor vision (say 20/100), will rarely require much in the way of a high plus magnifier (such as that given by a high bifocal add) for reading. The accommodative amplitude is usually ample to allow him to bring reading materials close enough to provide a sufficiently enlarged retinal image without requiring any further help from a lens. Kestenbaum pointed out that a good approximation of the near add required by a patient with reduced vision is the reciprocal of the visual acuity measured distance. Thus, an acuity of 20/100 would require a +5 diopter add to aid near work. For the child in the above example, more than sufficient accommodative power is still available to provide for this degree of magnification. On the other hand, as the child gets older and loses some of his accommodative amplitudes, the ability to magnify an object by holding it close diminished. The need to reconsider low visual aid in these patients periodically is thus self apparent (2).

There is at least one additional reason why shortening the focal distance for near viewing may aid the child with subnormal visual acuity. In the case of a child with accompanying nystagmus and poor visual acuity, the amplitude of nystagmus is almost always diminished during the act of convergency (3). In some cases, however, the degree of convergence required to significantly dampen the amplitude of nystagmus may be such as to place the focal distance very close to the patient's own eyes. As I shall discuss in more detail in a later section, it is apparent from objective eye movement recordings of patients with congenital nystagmus, that effective foveation and viewing occurs only during certain phases of the nystagmus (3). This usually coincides with the period of time during which the amplitude of nystagmus is at its least.

All of you who have worked with children with subnormal vision will have noted that some time or another many of these children will assume a marked head tilt or face turn when asked to perform demanding visual tasks. These abnormal head positions may be so extreme as to interfere with the development of good postural reflexes. The question therefore that is foremost in our minds is why should a visually handicapped child seemingly further impair his

general development by assuming these abnormal head positions? In the case of a child with no major visual handicap, abnormal head positions are most commonly associated with the attempt of the patient to place his head in a position to compensate for a paresis of one of the extraocular muscles, thus reestablishing bifoveal vision. However, this is rarely, if ever, the reason why children with subnormal visual acuity assume these abnormal head positions.

A substantial body of information now exists to demonstrate that the most common reason for children with subnormal visual acuity to assume an abnormal head position is to shift the position of fixation in such a way as to compensate for their concomitant nystagmus. Most children with subnormal visual acuity acquired from birth, other than those cortically insulted, will develop an associated nystagmus. The amplitude and wave form of this nystagmus is not uniform in all fields of gaze. In many of these patients, there is a marked position of preferred gaze that usually correlates well with the null zone of the nystagmus. The null zone of nystagmus is defined as the position in which the product of nystagmus frequency and amplitude is least. This can be quantitatively measured using objective eye movement recordings, and has been extremely useful in accurately determining the amount of surgery required to change the fixation preference of children with congenital nystagmus (3,4). Dell'Osso and Flynn have recently demonstrated that this type of surgery not only produces the expected shift of the null zone, but that in addition two other changes in nystagmus intensity occur that may be conducive to better visual acuity in these patients (4). The first of these is a broadening of the null region which provides a wider range of gaze angles with minimal nystagmus. This makes the actual gaze angle employed by the subject less critical and thus good acuity easier to maintain. The second finding is an overall reduction of nystagmus intensity outside the null zone. With this comes a corresponding reduction of effort to see on the part of the subject. From a practical point of view, it would seem that all infants with subnormal visual acuity associated with nystagmus and abnormal head position should be considered candidates for surgical treatment of their nystagmus until proven otherwise.

It is important, however, to point out that not all abnormal head positions assumed by children with subnormal visual acuity are the result of an attempt to find the null zone of associated nystagmus. Taylor has pointed out that children with juvenile cerebromacular disease will commonly take a chin up head position and fixate on a target as if they were

looking over the target position (5). This head position has been termed "overlooking" by Taylor, and he suggests that this position is assumed in an attempt for the child to avoid a central scotoma. We have noticed that this chin up head position may be seen in children with a number of visual handicaps other than juvenile cerebromacular disease. Although it is unclear at the present time whether Taylor's thesis is correct that this head position is an attempt to place the object of regard on a more sensitive area of uninvolved retina, it is clear that a number of infants with subnormal visual acuity assume abnormal head positions unassociated with a null zone of accompanying nystagmus.

Even more striking than the abnormal head positions assumed by some infants with poor vision is the head nodding seen in association with nystagmus. The specific association of head nodding with congenital nystagmus was described more than 80 years ago (6). Implicit in the discussion of the original cases of congenital nystagmus was the notion that the origin of accompanying head nodding was pathological and not compensatory. Recently the development of techniques to record head and eye movements simultaneously in these patients has readdressed this question.

It is noteworthy that in a study of a patient with spasmus nutans, head and eye movement recordings clearly demonstrated that the associated head movements were compensatory (7). That is to say, the head movements were in the opposite direction of the ocular oscillations and in effect completely stopped the eye-in-head oscillation. This was an entirely unexpected finding and challenged many previous clinical observations. Indeed, child psychiatrists who have evaluated children with spasmus nutans have suggested that the head movements represent attempts at auto arousal similar to those seen in autistic children. The unexpected finding in this case of spasmus nutans prompted the same investigators to study the problem of head and eye movement in patients with congenital nystagmus (8).

Inexplicably, in the case of congenital nystagmus, the associated head movement was found to be neither compensatory nor anti-compensatory. It was a superimposed oscillation, which coupled with the vestibulo-ocular reflex did not affect foveation or acuity. Whether this is true in all cases of nystagmus associated with subnormal visual acuity remains to be determined. However, at the present time most authorities agree that head shaking in association with congenital nystagmus and poor vision is probably not an attempt to improve foveation strategies. It is postulated that the head shaking has a common pathologic origin with the nystagmus,

and that just as in the case of isolated congenital nystagmus, wave form becomes altered with attention to permit periods of foveal fixation. The pattern of combined head and eye nodding in these patients provides similar periods of fixation. Further study of these patients is certainly warranted.

There is a small group of children often identified as visually handicapped early in infancy whose most remarkable physical finding is abnormal head thrusting. These patients have an ocular motor control abnormality termed oculomotor apraxia. Because these patients have difficulty initiating isolated refixation eye movements, they are frequently felt to be blind, particularly in the first few months of life, when visual function is ascertained by observations of ocular motor response to various visual stimuli. Subsequent development proves this not to be the case as the central resolving visual acuity of these patients usually is normal.

Studies of eye and head movements in infants with congenital oculomotor apraxia have also yielded unexpected information (9). Initial reports suggested that the patients with congential oculomotor apraxia turned their heads with a thrusting motion, thus dragging their eyes passively using only the vestibulo-ocular reflex. Thus, this syndrome was seen as the primary defect in the ability to generate effective saccadic eye movements. More recent studies have demonstrated that patients with congenital oculomotor apraxia have difficulty initiating saccadic eye movements with a fixed head position, but can initiate effective saccadic eye movements when the head is thurst in the direction of the new intended line of sight. Thus, the abnormal head movement can be seen as an aid in generating saccadic eye movements rather than a means to initiate alternative brain stem generated eye movements. It is perhaps important to emphasize that Taylor has recently reported that some infants in whom the diagnosis of congenital ocular motor apraxia was made were subsequently found to also have Leber's congenital amaurosis with significant visual loss (10).

Objective D-C eye movement recordings have provided a number of useful observations about ocular motor strategies used by children with visual handicaps. Although careful clinical observation may demonstrate these same movements, objective eye movement recordings have been essential in defining them more clearly. In the case of a nystagmus, associated with subnormal visual acuity, the work of Dell'Osso and Daroff (3) is most important. These authors have shown that the wave form of nystagmus changes when patients concentrate on a visual task. For example, when most patients with nystagmus are at rest

and not concentrating on a visual task, the wave form of the nystagmus is usually described as a saw tooth shaped nystagmus in which a fast and slow phase is easily identified. On the other hand, when these patients are made to concentrate on a visual task, the nystagmus is transformed to the so-called saddle shape (the "jerk nystagmus with extended foveation"). In this type of nystagmus, in between fast phases, a saddle shaped movement occurs giving the impression of a separate harmonic distortion usually at a slower frequency than the primary nystagmus. Improved foveation is felt to occur as the result of this alteration in nystagmus wave form and amplitude.

There are some infants and children with visual handicaps who challenge our very basic concepts of normal visual anatomy and physiology. A striking example of this is the case of patients with congenital hemianopia. A number of clinicians have noted these children frequently behave as if they have no defect whatsoever and are only identified in early adulthood as the result of routine screening for the military or other occupational positions in which formal visual field testing is required. Recently, quantitative studies of eye-head movements during visual search and fixation in patients with occipital hemianopia have begun to address the nature of these adaptations (11). These studies have shown that in those patients with acquired hemianopia, an eye search for targets in the blind hemifield occurs in a staircase pattern in which the eyes make small saccadic movements into the blind field with little or no head movements. These compensatory modifications in head movements and their synkinesis with eye movements are not a useful adaptation for finding and fixing targets in the blind hemifield in these patients. In contrast, the ocular motor strategy utilized by patients with congential hemianopia is quite different. These patients tend to eliminate all head movements and substitute a single large overshooting saccadic eye movement with a controversive drift. This ocular motor strategy appears to be more effective for these patients and may partially explain their apparent normal visual behavior, despite extensive lesions within the primary visual cortex.

This brings me to a discussion of what I consider to be the most interesting group of children with significant visual handicaps. This is the group of children said to be cortically blind. Long term observations of these children show a remarkable recovery pattern heretofore poorly documented and still only incompletely understood. Nevertheless, the entire question of plasticity of the nervous system becomes an essential issue in the evaluation and prognosis of these patients. Over the last 8 1/2 years,

we have followed a group of 53 cortically insulted infants at the University of California at San Francisco. I would like to share with you some of our findings and dilemmas as they relate to this interesting group of patients.

From the outset, it is important to emphasize that we have never seen a child with visual cortex insults who remained totally blind. However, it should also be stated that more recent long term studies of adult patients with visual cortex insults have also shown a variable degree of recovery (ref 12). Nonetheless, the degree of recovery in children does appear to us to be greater than it is in adults, albeit difficult to quantitate and completely study. The essential question must therefore be asked: "What are the adaptation mechanisms that allow children to recover from a visual cortical insult?" This brings us to a major argument currently unresolved among behavioral neurologists. Is the visual recovery seen primarily due to incomplete damage to the visual cortex and its relay systems, or does it occur as a result of non-geniculate striate systems, assuming primary visual functions?

In order to lay the groundwork for this discussion it is important to review some visual anatomy and physiology. You will recall that a substantial minority of the fibers of the optic tract, 20 - 30% in man, are not destined to synapse in the lateral geniculate body. These fibers and their connections are referred to as the extrageniculostriate system. The largest group of these nongeniculate fibers synapse in the region of the superior colliculi and pretectum. The only function that these fibers subserve that has been established beyond any question is regulation of pupillary size. It is readily apparent, however, that the light reflex of the pupil is unlikely to require 20 - 30% of all neurons of the optic tract. Furthermore, functions for the extrageniculate striate system have been proposed on the basis of animal experiments, but still remain to be completely validated in man. The primary suggestions for the function of these visual fibers have been:

1. They subserve a visual function essentially similar to that of the geniculostriate system, but cruder in its discriminations.
2. They are primarily important in the maintenance of a stationary optical image on the retina by means of reflex eye movements.
3. They are essential for the provision of visual feedback for cerebellar coordination of learning skilled movements.

4. They provide a collaboration with the geniculostriate system in higher visual functions and may in the case of insults to the geniculostriate system mediate useful visual function (ref 13).

Attempts to use electrophysiologic or computerized scanning techniques to document the presence or absence of cortical function in patients felt to be blind as the result of a visual cortex insult have not proven to be reliable. For example, it is well known that visual evoked potentials can still be successfully generated even after the primary visual cortex has been completely destroyed (ref 14). Similarly, it is clear that visual evoked potentials are of no diagnostic or prognostic significance in the evaluation of a large series of cortically insulted children (ref 15). Likewise, computerized axial tomography of the visual cortex is not capable of determining whether or not the visual cortex has been completely destroyed, particularly in the case of hypoxic encephalopathy, which is the most common cause of visual cortex dysfunction in childhood. Indeed, computerized axial tomography of children with apparent cortical blindness is oftentimes notably unremarkable. Moreover, preservation of only a small portion of the visual cortex (the so-called temporal crescent) might account for a significant amount of visual function seen in these patients (ref 16).

Despite these diagnostic dilemmas, there are a number of reasons why it is important to consider the possibility that the extrageniculostriate system may be important in the visual recovery of the cortically insulted child. Indeed there are a number of authorities who are convinced that the visual cortex is essential to what we recognize as cognitive visual experience is erroneous (ref 17 - 19). Moreover, behavioral observations of the visual recovery pattern of animals with complete surgical removal of the visual cortex have demonstrated a more dramatic recovery in infant vs. adult animals of the same species (ref 20). The dilemma of whether the apparent visual recovery of the child with visual cortex damage is due to incomplete structural damage of the cortex or to the ability of the extrageniculostriage system to assume visual functional responsibility remains unresolved (ref 21).

Whatever the mechanism responsible for the recovery of children with visual cortical insults, it is imperative that these children be viewed over the long term and that short term evaluations not be utilized to condemn them to a life without attempts at visual rehabilitation. A number of our children have experienced dramatic and significant visual recovery over more than a decade. One of the most difficult

aspects of this whole problem is that the recovery pattern of these children is not easily detected by standard ophthalmic tests. For example, many of these children recover the ability to identify single letters of large print as long as they are well isolated from adjacent letters. Most of these children recover the ability to name colors, and have no apparent defect of color vision, even in their remaining peripheral fields. These children detect moving targets in their peripheral field better than in their central field. Thus, the static central resolving acuity tests used so frequently in the ophthalmologists office cannot be performed by these children. However, the extent of visual function recovery in these children may be impressive.

I would like to conclude this paper by pointing out that recent investigations in adult monkeys have suggested that our view of the brain's potential for recovery may be grossly in error. The dominant view of the nervous sytem is of a machine with static properties. Recently Merzenich and co-workers have challenged this view (21). These investigators have been instrumental in changing our notion of how plastic the central nervous system of higher mammals is in adulthood. Their experiments have concentrated primarily on the topographic organization of tactile sensation in the adult monkey. Their experiments suggest that this pattern is not static, and that the brain's representation of touch sensation along a monkey's fingertips may move within a zone that is roughly 1,200 micrometers in diameter. Thus, the brain waves responsible for registering sensation of touch are not "hard wired" but remain unexpectedly fluid, even into adulthood. Although experiments have not yet been done on the visual system, Merzenich expects that similar findings and rules will apply there, even though the organization of its neural components is believed to be more rigidly anatomic. If truly general in the adult brain, these dynamic, self organizing properties eventually could be tapped for more effective restoration of lost functions after brain injuries, assuming that appropriate methods can be developed to make use of these insights. We should await with great interest the results of further experimentation in this area.

CONCLUSION:

Children with subnormal visual acuity use a number of physiologic adaptations in an attempt to improve their visual function. These include:

1. They shorten their focal distance for viewing objects at near, primarily to obtain magnification and/or to dampen concomitant nystagmus.

2. Abnormal head positions are taken primarily to establish the null zone of nystagmus with reduced amplitude and frequency. Less commonly, a chin up head position is seen in children with some forms of retinal degeneration. Whether this chin up head position is an attempt to place the object of regard on a less involved portion of retina and its neural connections has yet to be determined.

3. Head movements seen in patients with poor vision and nystagmus are probably not compensatory, but further studies are required. The head movements in children with spasmus nutans, in contrast, appear to be a compensatory mechanism. Head thrusting in congenital oculomotor apraxia helps initiate saccadic eye movements that cannot be initiated without accompanying head movements.

4. The oculomotor search strategy in congenital hemianopia is distinctly different from that of acquired hemianopia and appears to be an effective adaptation.

5. The long term follow-up of children with visual cortical insults demonstrates dramatic recovery in most cases. Whether this is the result of incomplete damage to the visual cortex, or whether it represents the ability of the extrageniculostriate system to assume primary visual function is yet undetermined.

6. The entire concept of neural plasticity is being extended to include the recovery seen in adult animals and research in this area may produce unique rehabilitation strategies for both children and adults with visual handicaps.

REFERENCES:

(1) Rubin, M.L. - Optics for clinicians. Gainsville, Florida. Triad, 1971, p.233.

(2) Tongue, A.C. - Low vision examination in children with visual impairment. J. Ped Ophth Strab. 1980. - 17:175.

(3) Dell'Osso, L.F., Daroff, M.D. - Congenital nystagmus wave forms and foveation strategy. Doc. Ophth 1975 - 39:155.

(4) Dell'Osso, L.F., Flynn, J.T. - Congenital nystagmus surgery: a quantitative evaluation of effects. Arch. Ophtha. 1979, 97:462.

(5) Taylor, D., Lake, B.D., Stephens R.: Neurolipidoses in Wybar K, Taylor D. - Pediatric Ophthalmology. Current Aspects. Marcel Decker. New York, 1983, p. 179.

(6) Aldrich, C.J. - Head nodding and head rotation usually associated with nystagmus in very young children. Am. J. Med. Sci., 1899, 117:158.

(7) Gresty, M., Leech, J., Sanders, M. - A study of head and eye movement in spasmus nutans. Br. J. Ophth., 1976, 60:652.

(8) Gresty, M., Halmagyi, G.M., Leech, J. - The relationship between head and eye movement in congenital nystagmus with head shaking: objective recordings of a single case. Br. J. Ophth. 1978, 62:533.

(9) Zee, D.S., Yee, R.D., Singer, H.S. - Congenital motor apraxia. Brain, 1977, 100:581.

(10) Moore, A.T., Taylor, D.S. - A syndrome of congenital retinal dystrophy and saccade palsy - a subset of Leber's Amaurosis. Br. J. Ophth. 1984, 68:421.

(11) Zangemeister, W.H., Meienberg, O., Stark, L., Hoyt, W.F. Eye-head coordination in homonymous hemianopia. J. Neurol. 1982, 226:243.

(12) Aldrich, M.S., Alessi, A.G.., Beck, R.W.. and Gilman, S. Cortical blindness in adults: etiology, diagnosis and prognosis. Ann. Neurol. 1984, 16:115.

(13) Brindley, G.S.., Gautier-Smith, P.C., Lewin, W. - Cortical blindness and the functions of the nongeniculate fibers of the optic tracts. J. Neurol. Neurosurg. Psych. 1969, 32:259.

(14) Spehlmann, R., Gross, R.A., Ho, S.U., Leetsma, J.E., Norcross, B.A. - Visual evoked potentials and post mortem findings in a case of cortical blindness. Ann. Neurol. 1977, 2:531.

(15) Frank, Y., Torres, F. - Visual evoked potentials in the evaluation of cortical blindness in children. Ann. Neurol. 1979, 6:126.

(16) Benton, S., Levy, I., Swash, M. - Vision in the temporal crescent in occipital infarction. Brain, 1980, 103:83.

(17) Lewin, R. - Is your brain really necessary? Science 1980, 210:1232.

(18) Aylward, G.P., Lazzara, A., Meyer, J. - Behavioral and neurologic characteristics of a hydrancephalic infant. Dev. Med. Child. Neurol., 1978, 20:211.

(19) Tuber, D.S., Bernston, G.G., Bachman, D.S., Allen, J.N. Associative learning and premature hydrancephalic and normal twins. Science, 1980, 210:1035.

(20) Stewart, D.L., Riesen, A.H. - Adult vs. infant brain damage: behavioral and electrophysiologic effects of striatectomy in adult and neonate rabbits. Adv. Psycobiol. 1972, 1:171.

(21) Campion, J., Latto, R., Smith, Y.M. - Is blind sight an effect of scattered light, spared cortex, and near-threshhold vision. The Behavioral and Brain Sciences. 1983, 6:423.

(22) Merzenich,M.M., Kas, J.H., Wall, J.T., Surm, Nelson, B.J., Felleman, D.J., - Progression of change following median nerve section in cortical representation of hands in areas 3b and 1 in adult owl and squirrel monkeys. Neuroscience. 1983, 10:639.

THE FUNCTIONS OF A LOW VISION CLINIC AND THE USE OF AIDS

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This morning I shall discuss the function and structure of a Low Vision Clinic, and the use of visual aids, with particular reference to the visually impaired child.

It is important that we have an operational definition of low vision, and several such definitions exist. Eleanor Faye defines low vision as "visual acuity, or visual field, falling below a norm --- not correctable by conventional spectacles -- producing a problem in daily life" Mehr and Fried define low vision as "reduced central acuity or field loss --- resulting in significant visual impairment from a performance stand-point." The definition assumes that the loss is bilateral, that some vision remains, and that the vision is not correctable with regular lenses. The essence of these definitions of low vision is that a significant visual handicap exists, and that significant usable residual vision exists also. Visual disabilities and handicaps describe limitation in personal skills, such as reading, mobility, and even eating, which result from visual impairment. Not everyone with reduced sight or visual impairment is a "low-vision" patient, and low vision aids are required only when the ability to perform needed visual tasks is compromised. Low vision aids are devices which improve the patient's performance of specific visual tasks.

In any given patient, a disease, or an injury, or an anomaly may produce a disorder in the visual system. This may result in impaired function of the visual system, and a consequent disability, or handicap. However, not everyone with visual impairment or impaired sight has a disability or a handicap, and many patients with reduced sight are not really low vision patients. Children are remarkable in their ability to adapt to visual impairment, and in many cases can compensate so well for an impairment that they have little disability and handicap. Indeed, their greatest handicap can be our lowered expectations of them.

A number of visual and ocular disorders, which undeniably produce visual impairment without great disability come to

mind. These include ocular albinism, juvenile retinoschisis, many cases of congenital nystagmus and congenital cataracts, mild and moderate degrees of optic atrophy, and some colobomata. Many children with these disorders keep up with their peers and have no major problems. The crunch often comes when they fail to meet the visual requirements for a drivers' licence.

Until the 1978 modification of the International Classification of Diseases, the population was classified as "sighted" or "blind". The I.C.D. in 1978 introduced a new classification consisting of "normal vision", "low vision"; and "blindness". The old, traditional dicotomy was unfortunate. If an individual failed to meet a standard of vision, often a visual acuity of 20/200 (6/60) he was classified as blind, and often treated as such, and significant usable residual vision was often ignored. There were cases of children with significant usable residual vision who were educated, sometimes in residential schools for the blind, as non-sighted individuals. We could say that they were "blinded by the definition". The importance of the inclusion of "low vision" in a classification of levels of visual importance is that it acknowledges the co-existence of visual impairment with significant usable residual vision.

Low Vision Clinics have been in existence for many years, but it is really in the past ten to fifteen years that significant numbers of these have come into existence. They now exist in hospitals, medical centres, and university departments of ophthalmology and optometry. As well, associations for the blind or visually impaired may have such clinics. The New York Light House Low Vision Service (The New York Association For the Blind) is an example and indeed a model for many clinics. Such clinics are staffed by ophthalmologists, optometrists, and someone who I will label the "low vision assistant". The success or failure of the clinic is in many cases dependent on the low vision assistant who must assume many roles. He or she will train the patient in the use of low vision aids, or whatever devices are used to enhance the patient's residual vision. She may have to direct the patient to services and resources both inside and outside the clinic, depending on its organization. For instance, visual enhancement may not be possible, and the patient may need vision substitution. Orientation and mobility instruction may be in order. The patient may need training in daily living and community skills, and the intervention of social workers, occupational therapists and vocational counsellors may be of benefit to the patient. The visually impaired child may need the specialized services of a teacher for the visually impaired, and may require low vision aids from a resource

centre such as the Provincial Resource Centre for the Visually Impaired. Thus, the Low Vision Clinic, and in particular, the "low vision assistant", may play a triage role, and direct patients to many different services. On the other hand, the Low Vision Clinic may simply provide low vision aids and training in their use to patients referred from many of these services -- the Visually Impaired Program at the British Columbia Children's Hospital being a case in point. The ophthalmologist in a Low Vision Clinic may serve as a consultant to other ophthalmologists, weighing the relative benefits and risks of surgical or medical intervention in a low vision patient, against the benefits of up-to-date low vision aids.

It would be very helpful if we knew the prevalence of visual impairment in the population. Unfortunately, we do not know this, and only have a variety of estimates of this statistic. The numbers of visually impaired persons will depend to a considerable extent on the definition of low vision. CNIB statistics for British Columbia and the Yukon would suggest that roughly 2 persons per 1,000 could be registered as legally blind. The Health Interview Study found that 6.6 persons per 1,000 had visual impairment sufficiently severe to prevent the reading of newsprint. These statistics seem almost trivial when we consider that in some third-world countries the incidence of blindness exceeds 200 per 1,000 of population.

Roughly speaking, about ten percent of the registered blind population in Canada, and in British Columbia, is under the age of 19. Thus, British Columbia has between 400 and 500 registered blind children. There may be four times as many partially sighted, but not registerable children in British Columbia. That is approximately 2,000 in the under nineteen age group. Fortunately, for reasons that we will come to, many of these children, adapt very well to their mild, or moderate, or sometimes severe visual impairment, and do not need much help.

It is also of interest to us to consider the causes of visual impairment in children. In the year 1900, approximately 30% of the institutionalized blind were there because of visual loss secondary to ophthalmia neonatorum that is, gonorrhea in the eyes of newborns. In 1908, the use of silver nitrate drops in the newborns eyes were legislated, and this public health measure almost eliminated this problem.

In the 1950's, a new epidemic arose. This was visual impairment caused by the retinopathy of prematurity, or retrolental fibroplasia. When it was discovered that this was

related to the administration of excess levels of oxygen to premature infants, and the oxygen levels were reduced to a minimum effective level, the incidence of R.L.F. was markedly reduced. Another epidemic was that of congenital rubella. The incidence of this cause of visual impairment has been reduced through immunization programs.

In their book -- Visual Impairment in Children and Adolescents -- Jan, Scott and Freeman document the causes of congenital blindness in British Columbia in the period up to 1973. 26% was caused by R.L.F., 9.9% by rubella, and 44% by known hereditary causes. Acquired blindness was caused by hereditary factors in 37.5% and by cancer in 26.4%. 15.3% were caused by injuries and poisoning, which would include child abuse and motor vehicle accidents.

(As a footnote, it should be pointed out the British Columbia Government stated during a convention which coincided with this conference, that it was its intention to introduce mandatory child restraint in motor vehicles. It will likely serve to reduce the incidence of acquired blindness caused in motor vehicle accidents.)

Another important point illustrated in the book by Jan, Scott and Freeman was the fact that over 60% of the children studied in their book had some residual useful vision.

To this point, we have considered the definition of low vision, its prevalence, and some of its causes. We should now turn to low vision aids and consider how they work. There are two things which can be done to improve the visability of an object. One is to enlarge its image, and the other is to enhance its contrast. For the most part, low vision aids do the former, and simply present to the eye a larger retinal image. For the most part, this can be accomplished simply by proximity. That is, holding the image ever-closer to the eye. For instance, a child with mild visual impairment cannot see the writing on the blackboard from the back of the room, but if he is seated at the front, he can read what is written. Similarly, the printed word can often be seen if it is held close enough to one's eye. Most children can focus fairly easily on material, even when it is held close to the eye, as they have great powers of accommodation. As we grow older, we lose this power of accommodation, and eventually all of us need some form of reading glasses or bifocals. Thus, an adult with impaired vision may need strong plus lenses to keep near objects in focus. Fortunately, a child seldom needs this, unless his visual impairment is severe. This is particularly so with the younger child. However, as the child gets older, his ability to focus or accommodate decreases

somewhat. He is confronted with ever-smaller print size. His vision may fail as a result of progressive disease, he becomes more self-conscious and may reject useful aids simply on the basis of their appearance.

There are other means of providing a larger retinal image which do not require ever-increasing proximity of object and eye. These aids include hand and stand magnifiers, closed-circuit television systems, and large print material.

Telescopes may provide the magnification of distance objects and when provided with a so-called reading cap, can also be used for near objects and reading.

It is striking how well low vision children cope with their visual impairment. In particular, children with congenital, or early acquired visual loss are very adaptable, and many spontaneously make the best adaptation possible. Because of their ability to accommodate and to see printed and other materials when it is held very close to the eye, relatively few children need reading aids. Nevertheless, some do benefit from the use of high plus reading lenses, and hand and stand magnifiers. Children use a variety of strategies to compensate for their visual impairment and Dr. Creig Hoyt, in a previous presentation, has discussed these. In some children, the plasticity and adaptability of the central nervous system permits them to compensate for disorders and injuries which would be devastating to the adult, or mature central nervous system. For instance, it is known that children who have extensive neurosurgical removal of, say, the cortex in one hemisphere of the brain, can function very well with only minimal evidence of a hemiparesis (one-sided paralysis or weakness). Similarly, some children with several visual and ocular anomalies or disorders, make visual adaptation which permits them to read print with a facility which cannot be explained by accommodation, high myopia, the pinhold effect of small pupils, or optimum head positioning with nystagmus. For instance, a girl with retrolental fibroplasia which has left her with no recognizable retinal landmarks, and nystagmus so irregular as to be chaotic, nevertheless can hold print within 2 inches of her eye, and read 1 M text easily. She completes university as a sighted reader. What has been the neural adaptation which has allowed her to extract meaning and information from images which would only be a blur to the normally sighted individual? Perhaps, through the visual system's capacity for storage and integration, she has been able to perceive continuity and stability from brief successive glimpses using, perhaps, information from so-called "transient" retinal ganglian cells, or a type of "Y" cells. I hope you will excuse this rather

obscure reference. My point is simply that an immature visual and nervous system can make adaptations and compensations which are impossible in the adult, or more mature system. In some children these adaptations defy any known explanation.

Low vision aids, be they spectacles, hand or stand magnifiers, telescopes, or even electronic aids such as closed-circuit televisions will only be accepted by a child if it helps him perform some needed task, and only if it enhances his visual efficiency. Thus, most low vision aids are task-specific. There is no one aid which improves anyone's overall visual efficiency. If, during the evaluation of a low vision patient, we fail to identify specific visual tasks and well-defined goals, it is unlikely that we will be very successful in rehabilitating that particular patient. For instance, the adult patient with age-related macular degeneration who wishes only to see better, is unlikely to be rehabilitated. However, a patient who wishes to read, may receive a variety of aids to accomplish this task. These could include high add reading glasses. Or, hand or stand magnifiers. Similarly, a child or student may have difficulty seeing a blackboard, or overhead projections. A monocular telescope may be applicable, and solve this specific problem.

I shall now discuss the types of low vision aids. These include:

-High-add Spectacles and Loupes
-Hand-held Magnifiers
-Stand Magnifiers
-Telescopes
    .Distance: Hand Held, Head Borne.
    .Intermediate: Hand Held, Head Borne.
-Absorptive Lenses
-Accessory Aids
-Closed Circuit Television, and other video or electronic magnifiers.

The cost of these aids range from a few dollars to several thousand dollars.

While some patients, in particular children, adapt very quickly to the use of the aids, training in the use of the aid is often required, together with follow-up to determine that the aid is being properly, and indeed is of benefit. Most Low Vision Clinics have a library of "loaner aids" which can be loaned to the patient prior to the final prescription of the aid. A loaner system permits considerable flexibility in the selection of an aid, and the patient does not need to make any financial commitment to an aid until its appropriateness and

utility has been established. In some cases, aids may be rejected because they are being inappropriately used. Follow-up, usually provided by the low vision assistant, can correct this, and with training of proper use of an aid, may lead to its acceptance. Training in the use of low vision aids and reinforcement of proper techniques is not only the responsibility of the personnel in a Low Vision Clinic. Indeed, the itinerant teachers for the visually impaired have a major role in instructing their students in the use of aids.

The most common low-vision devices are simply spectacles. These are generally high-plus lenses which allow objects, usually the printed word, to be held very close to the eye, producing a large image on the retina. Spectacle aids have the advantage of leaving the hands free, providing a wide field of vision, and permitting prolonged reading. They are available in both monocular and binocular forms, and are generally fairly acceptable. They do have disadvantages. They require fixed reading distance, which is usually quite short. This alone often leads to rejection, particularly by the older patient, who cannot change his/her reading habits. They have the added disadvantage of inducing poor posture, and forcing one to hunch over a desk or reading material. As well, the short distance often creates problems as the illumination is obstructed.

Hand magnifiers are familiar to all of us. Hand magnifiers have the advantage of permitting a variable work space, and a normal reading range, or distance. They are available and familiar to most of us, and lend themselves to short-term tasks. Hand magnifiers have the disadvantage that they have a reduced field of view. With some stronger hand magnifiers, only two or three words may be seen at a time. Hand magnifiers also require that both hands be occupied. Patients with tremors or arthritis, for instance, find it difficult to maintain the proper focal distance with a hand magnifier.

Stand magnifiers are magnifiers, like hand magnifiers, which are generally mounted on a rigid base, which fixes the distance between the lens and the object being viewed. They have the advantage of permitting variable work space, and because they provide a predictable focus, are useful for patients with tremors and arthritis. They also have specific uses in hobbies and in seeing details, for instance on maps. A child may use a stand magnifier as it will rest on his reading material on his desk, and will leave his hands free some of the time. The disadvantage of the stand magnifiers are their reduced field of view. Their reduced illumination, and the fact that they require some coordination of hand and eye as they, like a hand magnifier, must be moved along the

printed text.

Telescopic systems are another major class of low vision aid. Often these are monocular telescopes, but may be available as the binoculars which are familiar to us all. Most telescopic systems are hand-held, however some may be spectacle borne. Telescopic systems permit magnification of objects in the distance, and when the telescope is provided with an appropriate lens to be placed over the object, can provide magnification at intermediate and near distances. Telescopic systems have some major disadvantages which severely limit their use. The main problem is that they provide a very restricted field of view and, in fact, give the user "tunnel vision". One cannot walk about or enjoy mobility while looking through such a telescope, even if its power is low. The depth of focus of most telescopes is very limited. Hence, a telescope designed for distance viewing cannot be used at near, unless it is provided with a lens that is placed over the objective. While focusing telescopes are available, and quite useful, they are expensive and generally bulky. Telescopes, even those that are small enough to be spectacle borne, are quite conspicuous and their appearance alone may cause a child to reject them. As well, all but the simplest of hand-held monocular telescopes, are quite expensive. Recently, there have been many reports in the lay press regarding the use and efficiency of spectacle-borne telescopes. While these reports have the commendable effect of raising the expectations of the visually impaired, they are often exaggerated, and quite misleading. For instance, running under the headline "Once Blind Boy Now Bikes and Plays Hockey". Reports that a child with albinism received binocular spectacle-mounted telescopes. While these may be useful to the child for reading, the aid in fact would only handicap him in biking and playing hockey, activities which he could do before and without the telescopic aid.

Closed circuit television systems have now been employed as video magnifiers for the visually impaired. Although these devices are relatively expensive, they do offer considerable advantage to the individual with severely impaired vision who wishes to or must remain a print reader. In these systems, a television camera and monitor permit high, variable magnification of printed material and other objects. They allow adjustment of contrast, and reversal of polarity (switching from white on a black background, to black on a white background). As well, the patient can seat him, or herself, at a comfortable distance from the monitor and avoid the fatigue which is inherent in many of the optical systems. The main disadvantage of these video magnifiers is their cost and bulk. Nevertheless, I think the costs are reasonable, and

transportable systems are available. Many of these are currently on display in the exhibit area.

Electronic reading systems, such as the T.S.I. Viewscan system provides a small portable device which incorporates a small scanner which can be passed over text and a display screen which provides a bright, legible, highly magnified image.

Absorptive (tinted) lenses are often useful for the visually impaired. These are frequently prescribed for patients who have opacities in the ocular media which can cause glare at high levels of illumination. Some patients with macular degeneration prefer to be dark-adapted, and albinos may prefer reduced levels of illumination. This may depend on the amount of pigmentation the individual has. Patients with retinitis pigmentosa often prefer lenses which increase contrast. Lenses such as the NOIR Plastic lenses and the C.P.F.550 lenses are often useful. The individual response to tinted lenses is quite variable and one must proceed on a trial and error basis.

Many non-optical or accessory aids are available which can help with everyday activity. These, in part, include large print books and periodicals, black felt tip marking pens, signature guides and masking devices, such as the Typoscope which provides a slit in a black card which exposes only one or two lines of print. Visually impaired patients have variable illumination requirements, and illumination should be controlled for best comfort and visual acuity.

I have given you an overview of low vision aids. Constraints on time have necessarily made it a superficial one. I have touched on the major classifications of devices available as aids to the visually impaired. Fortunately, many of these aids are on display in the exhibit area, and those of you with specific interests can probably get your hands on them and try them out. For those of you who would like to read a relatively short dissertation on low vision, I would recommend a chapter on low vision written by Alfred Rosenbloom, Jr., M.A.O.D., in Volume 1 of the Principles and Practice of Ophthalmology -- Peyman, Sanders, Goldberg, Editors, W.B. Saunders Co., Philadelphia, 1980. A comprehensive and readable text on low vision is Clinical Low Vision Second Edition, edited by Eleanor Faye, M.D.F.A.C.S., Little, Brown, and Company, Boston/Toronto, 1984.

I hope you leave this lecture with the feeling that we can, and should, make use of residual vision. I hope I have made you aware of the many means, now available, for enhancing the visual performance.

RECENT ADVANCES IN OPHTHALMIC GENETICS

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ABSTRACT

McKusick in 1972 stated "genetic heterogeneity (two or more fundamentally distinct entities that share approximately the same phenotype) is the rule. If a disorder is thought to be a single entity, it usually means that the disorder is not well understood." The recent genetic revolution has proven this important principle again and again. The heterogeneity of clinical albinism, retinoblastoma, aniridia and retinitis pigmentosa have made accurate and specific ophthalmic genetic counselling difficult. Recent application of new scientific technology has given us measurable factors to use in further subclassifying the diseases of our patients. In particular gene mapping and linkage studies are proving a powerful adjunct to empiric counselling. Now biochemical, microscopic and electrophysiologic tests can ascertain the different forms of albinism. In some families with heritable retinoblastoma, estimation of blood levels of an enzyme, esterase D, can be used to mark the presence of the retinoblastoma gene. Three different chromosomal loci have been found associated with aniridia on chromosomes 1, 2 and 11. The gene for red blood cell catalase has also recently been mapped to 11p13 as has acid phosphatase on chromosome 2 and so in some families, these enzymes may serve as measurable markers for the aniridia genes.

The most recent advance lies in the discovery of a genetic probe for X-linked retinitis pigmentosa. This probe will be particularly useful to those females related to an affected male who do not know if they are carriers and who wish to have children. The probe is felt to be useful in 40% of cases provided genetic heterogeneity can be excluded by analysis of further families.

The increase in genetic knowledge in the general population coupled with an increasing desire to plan their families makes the advent of specific genetic counselling, in addition to empiric risk figures, most welcome. Our counselling is only as accurate as our knowledge of the genetic risk for each individual case.

INTRODUCTION

Ophthalmology and Genetics have had a long association extending over most of the present century and starting with Sir Archibald Garrod's description of albinism as an inborn error of metabolism in 1909.

The scope of the current caseload of ophthalmic genetic patients has been estimated in the United States to be 50% of new cases of legal blindness in children (less than 20 degrees of visual field or less than 20/200 vision in the better eye), and this gives a very large social impact. The recent genetic revolution has provided insights into many genetically determined diseases including those affecting the eye. I wanted to highlight four areas where advances have made major clinical impact - albinism, retinoblastoma, aniridia and retinitis pigmentosa.

ALBINISM

Albinism is a disease of considerable antiquity. Noah is reputed to have suffered from this condition. The individuals with this condition have nystagmus, reduced vision, photophobia, reduced pigmentation in the fundus, foveal hypoplasia, colour vision anomalies and aberrant visual pathway projections. Many patients have reduced skin and hair pigment in addition to the ocular changes. Albinism affects one in 20,000 of the world's population and is also widespread in nature. Now 10 forms of oculocutaneous albinism (hypopigmentation affecting eyes, skin and hair) have been described as well as four types of ocular ablinism (hypopigmentation, largely although not completely confined to the eye). As the affected individual's visual prognosis and the family's genetic risk differ in each case, further delineation of clinical genetic and laboratory criteria have been necessary. In 1961, Kugelman and van Scott (1) described a laboratory technique of oculocutaneous albino hair bulb incubation in L-tyrosine. Witkop and co-workers (2) were able to separate these patients into two groups - those in whom no pigment developed in the hair bulb (tyrosinase negative) and those in whom pigment did develop (tyrosinase positive). The tyrosinase negative oculocutaneous albino has a worse visual prognosis than the tyrosinase positive, who gradually over time will develop more pigment in eyes, skin and hair with improving visual acuity and reduction in nystagmus (3).

X-linked ocular albinism affects mainly the eyes and occurs in males only. However there may be some dilution of skin and hair pigment - sometimes enough to make distinction from a tyrosinase positive oculocutaneous albino difficult. The genetic and visual counselling in each condition will be quite different.

The description of the carrier state of X-linked ocular albinism in the obligate heterozygotes (for example the mother of an affected male) has been helpful. Her fundus will show an exaggeration of the normal tigroid pattern and on fluorescein angiography, "window defects" are seen in her retinal pigment epithelium. This is felt to be due to lyonization or random inactivation of one or other of her two X chromosomes. In other words, the areas of reduced pigment have pigment cells who have inactivated the normal chromosome and in the normally pigmented areas, the opposite has occurred.

Also microscopic examination of skin and eyes of X-linked ocular albinos has shown macromelanosomes in these tissues. This explains the associated moderate dilution of skin and hair pigment in this predominantly ocular condition and also provides the means to confirm the diagnosis separate from tyrosinase positive oculocutaneous albinism. The test will also be position in female carriers of the abnormal gene and can be used to counsel a female wishing to start a family that 50% of her sons would be affected and 50% of her daughters, although asymptomatic, carriers.

Until recently ocular albinism has only been described in males. Recently some families have been described with affected females with autosomal recessive inheritance (4). Macromelanosomes are not present.

Many human albinos have also shown an anomaly of their retinocortical projections. Instead of the normal decussation of right and left visual fields taking place from a vertical line of demarcation through the fovea, the decussation starts temporal to the fovea. This markedly increases the number of fibers crossing to the other side at the chiasm and decreases the ipsilateral projection. This may be shown anatomically in albino mammals and lower vertebrates and also in post mortem exam in the albino human. However, it is most easily demonstrated in the alert human albino using sophisticated electrophysiological testing of the visual evoked potential (VEP). This test may be helpful in elucidating the cause of the ablino nystagmus and other oculomotor anomalies as well as confirming the diagnosis of albinism.

Thus in the large clinically heterogeneous group of albinism biochemical, histological and electrophysiological testing can be used to determine which genetic type is to be assessed and counselled for.

RETINOBLASTOMA

Retinoblastoma is the commonest intraocular tumour of childhood and also shows genetic heterogeneity in having at least three clinical forms. This tumour has doubled in incidence in the past 50 years from one in 34,000 live births to one in 16 - 20,000 live births (5). The mortality is 8% in the U.S. and 100% in other areas due to socioeconomic and cultural factors. Although 25 - 30% of cases are bilateral and represent genomic mutations, only 5% of patients have a positive family history. This is probably a marked underestimate of the heritable load as of the 95% of cases presenting with no previous family history, later transmission within the family shows a further 10 - 15% of sporadic patients may actually have the heritable form of the disease.

The third clinical form of retinoblastoma is very rare but is associated with an interstitial deletion on the long arm of chromosome 13. The larger the deleted segment, the more severe the associated mental retardation, microcephaly, cardiopathy, absent thumbs and other malformations. Analysis of the karyotype will show the deletion.

Genetic counselling in retinoblastoma has been frustrating in the past because there has been no known measurable gene product to confirm the presence of the retinoblastoma gene. Patients presenting with bilateral disease or with a positive family history could be counselled that the inheritance pattern was autosomal dominant and the risk would be as high as 40% for further affected offspring. No antenatal test was available if they did decide to go ahead.

In addition, the 10 - 15% chance that a sporadically occurring unilateral retinoblastoma might actually represent a genomic mutation could not be further documented. Recent genetic breakthroughs will help us clear the counselling in these confusion areas. Recently the gene for retinoblastoma has been mapped to the long arm of chromosome 13 at 13q14 by family studies and linkage analysis (6). The locus for the enzyme esterase D has also been assigned to chromosomal region 13q14 (7). This close linkage between the retinoblastoma gene and that for esterase D means that, at least in some families, there is now a biochemical marker for the retinoblastoma gene.

How does the retinoblastoma gene produce cancer? Knudson in 1971 (8) analysed 48 cases of retinoblastoma which were uni- and bilateral. He found that the bilateral cases presented much earlier on average (15 months) than the unilateral cases (32 months). No new cases presented after 15 months. He hypothesized that in the bilateral (therefore heritable) group, a first mutation was already in place and only one more mutation was necessary for malignant transformation. Thus the first mutation would produce a retinal cell which was heterozygous for the retinoblastoma gene but functionally normal. This first mutation could be transmitted from generation to generation with autosomal dominant inheritance.

The second mutation would remove the remaining normal allele and so the cell would be homozygous for the retinoblastoma gene. This second mutation would occur in the retina in both heritable and sporadic forms and retinoblastoma would result. The reason sporadic retinoblastoma is nongenetic in 85% of cases is that the first mutational event also occurred within a retinal cell and not throughout the body. Thus in sporadic nonheritable retinoblastoma (9), two mutations would have to occur in the same retinal cell, thus accounting for later onset of tumorigenesis.

Knudson's theory has been corroborated in the study of a patient with bilateral retinoblastoma. Because it is bilateral it must be heritable and the patient should have the first mutation in all the body cells. This indeed manifested itself as 50% normal blood levels of esterase D (one of the gene pair having been deleted with the retinoblastoma gene). Even with high resolution banding, no visible deletion could be seen at 13q14 making a subvisual deletion possible. When the retinoblastoma tumour was grown in cell culture, two cell lines were found, each with completely missing 13 chromosome. There was no esterase D activity in the tumour. Thus the second mutation which caused tumorigenesis was associated with a deletion of the second retinoblastoma gene as shown by karyotyping of the tumour and esterase D measurements.

Cavenee and co-workers (10) have now used restriction fragment length DNA proves of chromosome 13 and shown that several karyotypic mechanisms for change could cause the second mutation and resulting loss of the normal allele.

The exact nature of the retinoblastoma gene is in question. It has been postulated to be a regulator gene. Further work on this important factor as well as the search for more markers closely linked to the retinoblastoma gene will make counselling exact for more families. At present esterase D is

only helpful in families where both parents are heterozygous for the two forms of esterase D. However now in informative families, esterase D levels can be used to predict affected offspring pre-and postnatally.

ANIRIDIA

The name aniridia actually means absence of the iris. In fact this is seldom the case as rudimentary iris tissue is usually present. It is, in fact, the signal for a phenotypically heterogeneous group of conditions. Aniridia can be inherited in an autosomal dominant fashion or as part of several syndromes (11). Visual acuity can range from very good to very poor and poor vision is usually due to associated anomalies of the retina and optic nerve rather that changes in the iris. In addition, aniridia can affect the anterior chamber, the cornea and the lens and these changes are usually seen slightly later. Besides the multitude of ocular features, aniridia can be associated with mental retardation, genital anomalies and Wilm's tumour of the kidney. The incidence is between 1 in 64,000 to 1 in 96,000 and two-thirds of affected children have an affected parent. The inheritance pattern is usually autosomal dominant but there have been rare families where autosomal recessive inheritance has been documented. One-third of cases are therefore sporadic and of these two-thirds of cases are new autosomal dominant mutations. Between 25 - 33% of patients who show congenital sporadic aniridia will develop Wilm's tumour prior to age three.

As this tumour can be detected by abdominal ultrasound while still at a treatable stage, the finding of aniridia means that these patients should have a urological examination and abdominal ultrasound every six months until age five to detect Wilm's tumour early. In 1964, Miller and co-worker (11) defined the association of aniridia with Wilm's tumour, hemihypertrophy and other congenital anomalies. In 1978, a deletion of the short arm of chromosome 11 was found in some of these children (12). There is not a full association in that the full aniridia, Wilm's tumour, mental retardation and genitourinary anomalies syndrome (UGR triad) usually has a deletion of the short arm of chromosome 11 but the deletion can be present without Wilm's tumour being present and one can also have the aniridia, Wilm's tumour syndrome without the 11p deletion. Recent gene mapping confirms that the chromosomal deletion is one the short arm of chromosome 11 at section 13 for the Wilm's tumour, aniridia association. The gene for autosomal dominant aniridia has been mapped to

chromosome 1 by linkage with Rh, Duffie and PGM loci. Linkage of acid phosphatase-1 to another gene for autosomal dominant aniridia has been shown on chromosome 2. Therefore there are a number of genes which are necessary for iris development.

The observation of chromosome deletion in association with a tumour is consistent with Knudson's two-hit hypothesis previously mentioned in the context of retinoblastoma. The first step would be a chromosome deletion which sets up the potential exposure of a mutated gene to a second mutation which would produce the tumour. In retinoblastoma, this occurs on the long arm of chromosome 14 and in aniridia on the short arm of chromosome 11.

As with retinoblastoma, until recently there were no biochemical markers for the aniridia gene. Recently the gene for red blood cell catalase has been mapped to 11p13 (13). This catalase is normal with a normal karyotype but can also be reduced in the aniridia, Wilm's tumour syndrome. As the aniridia, Wilm's tumour syndrome can occur either with an 11p13 deletion or with normal chromosomes as with the patient with retinoblastoma with a subvisual deletion, another marker for the presence of the gene would be very helpful. In the future, abnormal catalase levels may act as a marker to detect subtle chromosome 11 deletions.

The initial Knudson two-hit hypothesis has therefore been applied recently to another important ocular tumour association.

RETINITIS PIGMENTOSA

Retinitis pigmentosa is the name given to a group of retinal degenerations characterized by progressive visual loss, night blindness and constriction of the visual field. It is not at all uncommon with a world prevalence of one to two individuals per 5,000 population.

Thirty-six to 48% of cases are isolated with no family history and may represent phenocopies or new genetic mutation of autosomal recessive, dominant or X-linked recessive modes of inheritance. X-linked recessive inheritance seems to vary in incidence in different countries but a recent statistic is 14 - 22 % of cases in the United Kingdom are inherited in an X-linked manner (14).

The X-linked form is one of the most severe with an onset in the first decade and severe visual handicap by the third. Males only are affected in youth. However examination of obligate carrier females (for example the mother of an affected male) can demonstrate fundus changes. This carrier state was first recognized by Falls and Cotterman in 1948 (15) and has been expanded and documented by more recent authors (16, 17).

The most characteristic changes were segmental areas of atrophy in the pigment epithelium with pigment migration into the retina. The retinal periphery could appear granular and have white dots over it. Some of the obligate carrier female fundi showed frank retinitis pigmentosa however, ERG and EOG changes could be present in these individuals.

The importance of detecting the carrier females is that 50% of their male offspring will be affected with this severe blinding condition.

Advances in molecular genetic technology means that the location of disease genes can be approached through linked genetic markers. The defective gene for X-linked retinitis pigmentosa has been shown to be on the short arm of the X chromosome. The marker showing this is a DNA probe L1.28 corresponding to a small fragment of the X chromosome. This fragment has a profile which makes it identifiable and therefore isolatable by bacterial restriction enzymes. Two variants, A1 and A2 have been traced through five families and correlated with the pedigree. The abnormal X-linked gene is linked to one or other variant of the L1.28 probe in each family studied (18).

The importance of this marker for the abnormal gene is that female carriers and the daughters of known carriers or affected males have the most to gain. These ladies, if they do carry the abnormal gene, would then know that they had a 50% chance of producing affected males.

There are, however, some limitations in the application of this technique. It is possible that there may be more than one gene for X-linked retinitis pigmentosa. If no affected male relative is available to check which form A1 or A2 is linked to the disease gene then testing the carrier female, will not be helpful. The other point is that the affected male has to be heterozygous for the marker. Therefore the probe is probably useful in around 40% of cases provided genetic heterogeneity can be excluded by analysis of further familes.

In the future the goal will be to find a genetic probe which will identify the mutant gene in a more specific way than the present marker does.

This latter application of molecular biology in genetics and ophthalmology is a perfect example of how the marriage of genetics and ophthalmology is becoming closer as the century extends. Application of these techniques to other forms of retinitis pigmentosa and other potentially blinding genetics diseases may help to reduce the incidence of blindness in children from genetic causes.

REFERENCES

(1) Kugelman, T.P., Van Scott, E.J., - J. Invest. Derm, 1961, 37, 73.

(2) Witkop, C.J. Jr., Van Scott, E.J., Jacoby, G.A., (1963). - "Evidence for Two Forms of Autosomal Recessive Albinism in Man." Proc. Second Int. Cong. Human Genet. Rome, 1961, Institute Gregor Mendel, Rome, p1964.

(3) Jay, B., Carruthers, J.D.A., Treplin, M.C.W., Winder, A.F., - Human Albinism". Birth Defects original Article Series, 12, 1976, 415-426.

(4) O'Donnell, F.E.., King, R.A., Green, W.R.,Witkop, C.J. Jr., - Arch. Ophthal. 1978b, 96, 1621.

(5) Rootman, J., Carruthers, J.D.A., Miller, R., - "Retinoblastoma An Overview: Histopathogenesis and Growth, Genetics, Cytogenetics, Cellular Mechanisms, Clinical Features, Management, Research and Future Considerations." In press.

(6) Sparkes, R.S. et al: - "Gene for Hereditary Retinoblastoma Assigned to Human Chromosome 13 by Linkage to Esterase D." Science, 1983, 219: 971-973.

(7) Sparkes, R.S. et al: - "Regional Assignment of Genes for Human Esterase D and Retinoblastoma to Chromosome Band 13q14." Science, 1980, 208: 1042-1044.

(8) Knudson, A.G., - "Mutation and Cancer." ROC Natl Acad Sci., 1971, 68:820.

(9) Benedict, W.F. et al: - "Patient with 13 Chromosome Deletion Evidence That the Retinoblastoma Gene is a Recessive Cancer Gene." Science, 1983, 219: 973-975.

(10) Cavenee, W.K., Dryja, T.P., Phillips, R.A., Benedict, W.F., Godbout, R., Gallie, B.L., Murphree, A.L., White, R.L. - "Chromosomal Mechanisms Revealing Recessive Alleles in Retinoblastoma." Nature, 1983, 305: 779-784.

(11) Nelson, L.N., Spaeth, G.L., Nowinski, T.S., Margo, C.E., Jackson, L., - "Ariridia A Review." Survey of Ophthalmology 1984, Vol. 28, No. 6, 621-642.

(12) Hittner, H.M, Riccardi, V.M., Francke, U. - "Aniridia Caused by Heritable Chromosome 11 Deletion." Ophthalmology 1979, 86, 1173-1183.

(13) Junien, C., Turleau, C., DeGrouchy, J. et al: - "Regional Assignment of Catalase (CAT) Gene to Band 11p13. Association With The Aniridia-Wilms Tumour Gonadoblastoma (WAGR) Comples." Ann. Genet, 1980, 23: 165-168.

(14) Jay, M. - "On The Heredity of Retinitis Pigmentosa." Brit. J. Ophthal. 1982, 66, 405-416.

(15) Falls, H.F., Cotterman, C. - "Choroidal Degeneration. A Sex-linked Form in Which Heterozygous Women Exhibit a Tapetal-like Retinal Reflex." Arch Ophthalmol, 1948, 40:683-703.

(16) Bird, A.C., - "X-Linked Retinitis Pigmentosa". Brit. J. Ophthalmol. 1975, 59:177-199.

(17) Jay, B., Bird, A.C., - Trans. Amer. Acad. Ophthalmol. Otolaryngol. 1973, 77, 641.

(18) Bhattacharya, S.S. et al: -"Close Genetic Linkage Between X-Linked Retinitis Pigmentosa and a Restriction Fragment Length Polymorphism Identified by Recombinant DNA Probe L1.28." Nature, 1984, Vol. 309, 253-255.

BLINDNESS IN CHILDREN: EPIDEMIOLOGY AND PREVENTION

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Abstract

"Epidemiology is the study of the distribution of disorders in a population, together with an examination of how the distribution varies with particular environmental circumstances" (Rutter). It is one of the basic sciences of population-based medicine. We have used it to survey disorders that lead to congenital blindness in children in British Columbia, to study causal processes, and to determine whether particular disorders are becoming more or less common. Have rubella immunization programs and advances in neonatal care reduced the occurrence of congenital blindness due to maternal-fetal rubella infection and retinopathy of prematurity? Are there other prevention programs we should be developing to reduce blindness? These are some of the research questions that epidemiological studies can address.

METHODS AND MATERIALS:

Our observations are based on clinical studies in B.C. from 1944 to 1984. The study population includes anyone born in B.C. who developed legal blindness, both congenital (CB) and acquired (AB), while in the 0-19 year age group. All of the children have been examined by a multi-discipline team in Vancouver. Particular attention has been given to the degree of visual impairment, definition of the ocular lesion, the cause of blindness and the presence of associated handicaps. The findings are transferred to a pre-coded data form, then added to the data base in the computer at U.B.C.

The main source of identification of the children were the CNIB, the B.C. Health Surveillance Registry, and the health records of the Children's Hospital (old and new) and the Health Centre for Children of the Vancouver General Hospital. The majority of the children are know to one or two paediatricians who have participated in the multi-discipline assessment, and all have been seen by ophthalmologists.

The diagnostic classification system used to code the etiology and the ocular lesions was published by the National Society for the Prevention of Blindness Classification of Causes of Severe Vision Impairment and Blindness. The Use of this classification of cause and the site and type of ocular lesions enables different investigators to collect data in a consistent manner thereby allowing comparison of findings. The classification divides the cause of blindness into six subgroups:

1. Infectious diseases.
2. Injuries, poisonings.
3. Neoplasms.
4. Diseases, disorders NEC (not elsewhere classified).
5. Prenatal influence NEC
   a) Hereditary
   b) Congenital origin NEC
6. Etiology indefinite/not reported

The site and type of ocular lesions are similarly divided into eight subgroups:

1. Eyeball in general
2. Cornea, sclera.
3. Lens.
4. Uveal tract.
5. Retina.
6. Optic nerve.
7. Vitreous.
8. Indefinite/not reported

RESULTS:

There are 671 individuals in the study population, divided into CB (556) and AB (115). Males predominate in both groups, particularly in the acquired groups.

The gap between parental suspicion and age of professional referral for assessment and management is wide. It is encouraging that consistent efforts to narrow this gap are having some effect.

Etiology:

The major cause of CB is Prenatal Influence NEC followed by Injuries, Poisonings and Infectious Diseases. Prenatal NEC accounted for 50 percent of cases from 1945 to 1954, but this percentage has risen to between 70 and 80 percent during the period 1965 - 79.

Prenatal Influence NEC divides into hereditary and congenital subgroups. The hereditary cases are twice as common. Approximately 40 percent of these genetic cases had a second reported case in the family. The congenital subgroup has increased while the genetic group has fallen from 1970-74 to the present time.

Retinopathy of prematurity and infections have played important roles in the past. There have been several children with retinopathy of prematurity and maternal rebella infection since 1980.

Ocular Pathology:

The site and type of ocular pathology in CB and AB has shown an increase in lesions of the optic nerve and a decline in lesions of the lens and retina. In CB the increase in the optic nerve lesions appears to have started in 1955-65 and has increased to 1975-79. The retinal lesions accounted for over 40 to 60 percent of the lesions in the five-year periods 1945-49 and 1950-54 but have fallen to about 20 percent since that time. The lesions of the lens accounted for over 30 percent of cases in 1955-59 but have progressively declined.

Further breakdown of the optic nerve lesions in CB into its subcomponents (optic nerve atrophy, other affections of the optic nerve and nystagmus) shows a variable proportion of these subgroups across time. Congenital optic nerve hypoplasia (CONH) is an important member of the second group.

Associated Handicaps:

About one-third of the CB group have no associated handicaps; over 40 percent have none in the AB group. The commonest handicaps are mental retardation, cerebral palsy, epilepsy, and hearing loss. There is evidence of fewer handicaps in the Injuries, Poisonings group during later years.

Incidence Rates:

The number of children born in B.C. during the study period increased but the birth rate has fallen. What number of blind children have been born in B.C. during this span? Has the number risen in proportion with the population or has it fallen? In other words, what has happened to the incidence rate of CB? The incidence rate of CB showed a sharp increase during the early 1950's

associated with the epidemic of retinopathy of prematurity. This produced nearly 1 case of CB per 2,000 live births. Since that time the incidence rate of CB has remained fairly steady at about half that level (0.4 per 1,000 live births). There has been a decline during the last two five-year periods but we probably should let another five years go by before we feel confident that this is reliable. There is the possibility that late reporting could increase the number of cases during the period 1975-79. At the present rate, approximately 18 cases (45,000 x 0.4) per year of CB are added in B.C.

PREVENTION:

The number of children with retinopathy of prematurity resulting in CB has clearly fallen. Those cases that do occur are nearly all in very low birthweight infants. The importance of the prevention of low birthweight is readily evident (primary prevention). The cause of retinopathy of prematurity remains unclear and research in this area is of the utmost importance.

In spite of an effective preventive program for maternal rebella infections during pregnancy, children with congenital rubella persist although less often than before. The importance of rubella immunization of young females and the routine preconception testing for rubella (rubella HI test) and immunization are obvious.

The dominant role of genetic disease in the physical disorders of the affluent population is again emphasized in this study. Genetic counselling should be available to this population of parents. While this will not eliminate CB or AB due to genetic cause, families with CB and AB secondary to either dominant and recessive modes of inheritance can be offered some measure of control. It is clearly important to develop regional expertise in ophthalmological genetics.

Finally, the cause of congenital optic nerve hypoplasia remains a mystery and a challenge. What is the meaning of the low maternal age reported in these cases? The study of this etiological clue seems warranted.

REFERENCE:

Rutter M. Surveys to Answer Questions:
Some Methodological Considerations in P.J. Graham (Ed.)
Epidemiological Approaches in Child Psychiatry.
London, Academic Press 1977.

FILTERS FOR PROTECTION, COMFORT, THERAPEUSIS AND VISION ENHANCEMENT

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INTRODUCTION

Absorbing filters in the form of tinted spectacle lenses, either prescribed or obtained over the counter, are used for a variety of reasons. These include comfort in certain lighting environments, reduction of glare, protection from electromagnetic radiation (with and without impact protection), cosmetic enhancement and or as a status symbol. In addition filters which eliminate certain bands in the visible spectrum have been advocated to enhance visual performance of sports, certain vocation purposes and in patients with visual impairment due to a variety of hereditary and acquired ocular disorders. Filters have also been introduced with the objective of retarding the progression of retinal degenerations, such as retinitis pigmentosa (RP).

The selection of sunglasses frequently is based on fashion, peer pressure and/or advertising material rather than on the optical properties of the lenses. The appropriate prescription of tinted spectacle lenses requires a knowledge of the natural or man-made hazardous environment, other factors which may influence an individual's sensitivity to optical radiation, optical characteristics of the eye, disease mechanisms (if any) and the spectral transmittance characteristics of available lenses.

Optical Radiation

Optical radiation is that part of the nonionizing electromagnetic spectrum extending between a wavelength of 100 nm to 1 mm which includes ultraviolet (UV), visible and infrared (IR) radiation. For radiation biological purposes UV is subdivided in three ranges: UV-A, UV-B, and UV-C; and infrared into IR-A, IR-B and IR-C (Fig.. 1). Sources of optical radiation include sunlight, lightning lamps, arcs, flash tubes, lasers and hot (incandescent) sources. The effects of optical radiation on ocular tissues vary with waveband; for a particular wavelength to produce changes in a given structure it must reach that structure and be absorbed

by it. Total and direct transmittance of the normal human eye is presented in Fig. 2.

Optical radiation interacts with biological tissues by being absorbed, transmitted, reflected, scattered and/or diffracted, in accordance with the various laws obeyed by electromagnetic radiation. The photobiological effects on the eye may be acute or chronic, reversible or permanent.

Optical Radiation Effects on the Eye

Earlier workers stressed the need to protect the eyes from near infrared radiation. In recent years, it has become increasingly apparent that the effects of ultraviolet radiation are much more detrimental to the eye and vision. Epidemiologic studies (Clear et. al. 1979) suggest that UV is the major factor in the development of pterygium. It has been found that the prevalence of pterygium increases to more than 10% in equatorial regions. Pingueculae show similar histologic changes to pterygia and since they too occur in tissue exposed to environmental optical radiation, UV may be a contributing etiological factor. Exposure to suprathreshold levels (Pitts et al. 1977) (Fig. 3.) of UV results in photokeratoconjunctivitis (photokeratitis, snow blindness, arc eye, photophthalmia). The symptoms of extreme pain, photophobia, blepherospasm, profuse tearing and reduced visual acuity are usually far more dramatic than the actual corneal damage which consists of loss of superficial corneal epithelial cells, autolysis of wing cells (Cullen, 1980) and with almost total desquamation of central corneal epithelium at high levels of radiant exposure. This results in edematous corneal swelling and loss of transparency. As with many types of corneal damage there is a secondary response in the anterior uvea resulting in aqueous flare. Fortunately the cornea is resilient and returns to normal within days. Some patients complain of photophobia following resolution of photokeratitis and this may be due to endothelial cell damage by UV-B (Cullen et al, 1984). Chronic corneal exposure to UV may be a factor in droplet keratopathy and some corneal dystrophies.

Pitts et. al. (1977) were able to produce acute anterior subcapsular cataracts (Fig. 4) with a single exposure of narrow band UV between 295 and 320 nm offering support to the earlier work of Bachem (1956) who found repeated high doses of UV between 293 and 313 nm were cumulative and cataractogenic. Studies using UV laser (MacKeen et al. 1973; Ebbers & Sears 1975; Zuchlich and Connolly 1976) have demonstrated that permanent cataracts can result from a single high irradiance exposure to narrow band UV longer than 290 nm at comparable

radiant exposure levels.

The effects of chronic exposure to UV-A at ambient environmental levels have been implicated in the development of age related cataracts. Biochemical studies by Lerman (1972), Zigman et al (1972, 1973) and others (Spector et al. 1975) provide evidence that near ultraviolet radiation over a long period can cause an increase in isoluble proteins in the crystalline lens, and through photooxidation of aromatic amino acids in the lens proteins lead to the formation of cataract. Geographic epidemiologic studies have shown that cataracts occur with greater frequency at latitudes where UV levels due to solar irradiation are most intense (Zigman et al. 1979; Hollows and Moran, 1981; Weale 1982). Due to the absorption characteristics of the cornea and lens very little UV light incident on the eye reaches the retina of a phakic eye except in the very young. However babies and aphakics (those who have had cataracts removed) are potentially susceptible to the very damaging effects of near UV on the retina.

Visible light levels which are hazardous to the retina and in particular to the fovea are uncomfortable to look at and the blink reflex (~0.1s) and other aversion responses usually protect the normal eye. However individuals do look at hazardous sources such as the sun (eclipse blindness), arcs and lasers. The old view that only the thermal hazard was important when considering the retina has been shown to be erroneous by Harwerth and Sperling (1975) Lawwill et al (1977) and Ham et al (1979, 1980, 1982). Blue light is several orders of magnitude more harardous to the retina than IR. Pitts et al (1983) exposes rabbits for extended periods of light from "cool white" fluorescent tubes and evaluated the eyes using the biomicroscope, ophthalmoscope, light and electron miscroscope. They found mild damage to corneal epithelium and endothelium and lens. Eight hours of exposure produced mild retinal edema whereas twenty hours resulted in damage to the photoreceptors. However, when their findings are placed in perspective it can be concluded that fluorescent lamps are safe when used properly.

Unlike the effects of UV radiation which are usually photochemical with a corresponding latent period between exposure and clinical response the effects of IR are thermal and immediate, involving the outer eye, the ocular media, iris, retina and choroid. The damage to the cornea is initially epithelial desication followed by protein coagulation of the epithelium and anterior stroma; however the sensation of heat and drying cause reflex lid closure to occur prior to coagulation (Geeraets et. al 1960). Duke-Elder (1972) states that even "moderate" levels of IR result in

aqueous flare, hyperemia and miosis and ultimately permanent damage to iris tissue. Acute irradiation with various optical sources which "heat load" the anterior lens (lasers, arcs, IR sources) can cause the crystalline lens to opacify. Direct exposure causes exfoliation of the capsule and opacification of the underlying anterior subcapsular cortex due in part to damage to the anterior epithelium (Pitts & Cullen, 1981). The classically described IR posterior subcapsular cataract is not typical of optical radiation cataracts and may be due in part to heat stress induced systemic metabolic changes.

A large number of drugs and other chemicals are known to increase the skin's sensitivity to optical radiation, partricularly UV-A. Similar responses have been demonstrated in the retinas of rodents and current research is investigating whether thresholds for UV damage in the lens and cornea are lowered by acute and chronic doses of known dermal photosensitizers.

Glare

Glare is the unpleasant dazzling sensation produced by bright light sources. The luminance required to produce glare varies with the angular subtense of the source at the eye, location in visual space and the luminance of the surround. Discomfort glare is usually associated with sudden exposure to a bright source and elicits reflex blinking and other aversion strategies. Glare which interferes with vision is termed "veiling" or "disability" glare and subjectively appears as a luminous haze over all or part of the visual field. Glare is increased by Mie and Raleigh scattering, fluorescence and reflections in the eye. The consensus is that blue and green wavelengths are somewhat more uncomfortable and disabling than yellow and red.

Tinted Lenses

The prescription and provision of tinted ophthalmic lenses has been, and continues to be, an important aspect of optometric practice. Whether the tinted lens is for cosmetic, sunglass, occupational, environmental, vision enhancement or therapeutic purposes, it is important for the practitioner to be familiar not only with the range of tints available but also the manufacturing processes and the absorptive properties of the tinted lenses, so that the most appropriate choice may be made.

There are three general approaches to tinting ophthalmic lenses. The solid or through-and-through tint is produced by adding metallic oxides to the constituents of the glass prior

to fusion of the mixture. Such colored glasses have the advantage of long-term stability of the tint with good reproducibility between production lots. However, such glasses used in high-power single vision lenses, or in any fused multi-focal lens design, will produce lenses with non-uniform density of tint, being denser in thicker areas.

White (ie: colorless) glass may be vacuum coated with a thin film of colorant. Such tints are relatively stable over long periods of time and uniform over the entire lens. They may, over a long period of time, be worn away or scratched during the course of normal use. They can generally be removed and replaced as desired.

Plastic lenses are generally tinted by immersion in hot aqueous dye solutions for a period of time which increases with the density of tint desired. The dye is absorbed and absorbed by the surface layers of the lens. Uniform color is achieved over the entire lens. Certain dyes are less chemically stable than others, consequently, tinted plastic lenses may show changes with time. This is especially true of grey plastic lenses, which over a period of years, take on a reddish hue, as the green dye constituent breaks down. Dyed lenses may be bleached and redyed as desired.

Ultraviolet-absorbing materials are incorporated into UV protection lenses such as UV400 and Lite Gard UV. Although these are plastic lenses, the active constituent (UV inhibitor) is mixed with the CR-39 components prior to polymerisation of the resin, in a manner analogous to the addition of the photochromic silver halide in the photochromic lenses, or the solid tint metal oxide to a glass mix prior to fusion.

Each type of tinting process has advantages and disadvantages. Solid tints are permanent and generally do not vary significantly between production lots. They do have significant disadvantages however. Lenses of high vertex power show changes of tint density across the lens according to Bouguer's law (thicker lens substance has greater tint density), as do fused multifocals with solid tinted carriers. They are also generally available only in restricted power ranges. Coatings are uniform across the lens and can be removed, replaced or changed as desired or as they wear off. However, they vary between laboratories and may change with time.

Given the number of colorants and tinting methods available to optical laboratories and lens manufacturers, it is not surprising that a given popular tint may be produced in both

glass and plastic lenses. Our data demonstrate (Chow and Cullen, 1983) that although the visual impression of such lenses may be the same, the actual spectral transmittance characteristics may differ considerably. An example would be the differences seen between the curves for Trucolor and the Grey 3 polycarbonate lenses in Fig. 5, two lenses which visually appear similar in color and absorption. Both the practitioner and patient should remember that, "What you see is not necessarily what you get" - unless you specify the tint exactly!

Earlier published spectral transmittance data for tinted spectacle lenses (Kors & Peter, 1972; Garner, 1973, 1974; Borgwardt et al, 1981; Dain et al, 1981) have been limited to the near ultraviolet (300 to 400 nm) and visible light (400 to 789 nm). The effects of UV radiation on the anterior segment and the retina have been well documented, and there can be no doubt that high levels of near IR radiation (780 to 2500 nm) can also damage ocular tissues. Chou et al (1984), Chou and Cullen (1983, 1984a, 1984b) and Cullen and Chou (1984) have derived spectral transmittance measurements in the far ultraviolet (200 to 300 nm) and the near infrared (to 2500 nm), for ophthalmic, contact, special purpose, and over the counter lenses.

Vision Enhancement

The use of filters which restrict the visible spectrum, particularly at the blue end, has been popular for many years. Yellow goggles or sunglasses have been used to enhance visual performance by skiers, automobile drivers (particularly at night), hunters and other shooters. Despite subjective claims of improved performances by the users, Wyszecki (1956) found no theoretical basis for improved detectability using any type of colored lens. Neumueller (1936) was unable to detect any effects on visual acuity produced by tinted lenses. Lauer (1951) reported that, in simulated night vision experiments, while some colours reduce glare there is also a corresponding reduction in visual acuity. In daylight conditions Reid (1955) found that neural amber and green tints had no effect on visual acuity. More recently Kiney et. al. (1980), evaluated the effects of yellow and neutral tints on visual functions other than letter acuity and found that although stereoacuity was unaffected, there were significant improvements in the perception of low contrast contours with yellow filters. They also discovered that although contrast sensitivity reaction times were equivalent for yellow and luminance-matched neutral tints at high spatial frequencies, faster reaction times were found at lower frequencies with the yellow filter. In addition, for low contrast targets of

mid-range spatial frequency with light surround, the superiority of the yellow goggles was confirmed. Yap (1984) confirmed that contrast sensitivity was improved with a yellow filter under photopic conditions but did not find a significant effect at most spatial frequencies under mesopic conditions. These findings offer an explanation for subjective reports of improved visual perception and once more emphasize the inadequacy of letter charts (visual acuity) as a measurement of functional vision. The theoretical explanation of improved contrast sensitivity may be biophysical or physiological. Elimination of the blue end of the spectrum decreases the effect of chromatic aberration on the retinal image and some of the scatter effects in the ocular media. There is also the possibility that yellow lenses eliminate the inhibitory blue cone input for certain visual functions resulting in physiologically stronger signal. The use of red and magenta (red and blue transmitting) filters in the form of a spectacle or contact lens as aids for improved chromatic discrimination in colour defectives has been reviewed recently by Egan (1982).

It is also claimed that patients suffering from certain ocular conditions benefit from specific tinted lenses by increased visual comfort, improved contrast, improved visual acuity and better light adaptation. Unfortunately, double masked clinical trials are almost impossible to design and much of information available is either anectdotal or subjective. Hoeft and Hughes, (1981) in a study of one hundred adult low-vision patients with light sensitivity associated with a variety of ocular diseases, asked the patients to choose the subjectively best from a selection of five filters. Patients with glaucoma, senile macular degeneration (SMD) and diabetic retinopathy tended to select filters of relatively high transmission with no preference for color. Albinos preferred amber filters, and those with RP preferred dark amber filters. Patients with old retinal detachments, optic atrophy, and cataract showed no filter preference except that, as with all groups, they disliked the dark green filter.

Government funding has permitted the establishment of the Centre for Sight Enhancement at the University of Waterloo. This has evolved from Canada's largest and most active low vision clinic and includes an opto-electronic sensory aid programme. The philosphy of parallel (optometric and surgical/medical) care has been retained. It is hoped that some answers as to why low vision patients enjoy enhanced visual perception through certain filters will be revealed by the active research in the Centre.

Bier (1983) has stressed the need for psychophysical

procedures to assist in the selection of the appropriate filters for RP patients and also to enhance current subjective and electrophysiological monitoring of the progression of the disorder. Based on his own extensive experience he advocates a modified Young's chromatic threshold test, the photostress test and a subjective preferred filter test. He cautions that a subjectively preferred filter may not be appropriate for spectral radiation protection.

In recent years a series (CPF™) of photochromic filters has been introduced by Corning which eliminates virtually all ultraviolet radiation and blue light. Three CPF lenses are available (Table 1) with luminous transmittance varying from 47% (yellow/amber) in the lightened state to 5% (deep red) in the darkened state (Fig. 6). The absorptance properties of these lenses are such that they provide excellent protection against UV and blue light hazards, and due to photochromic properties, reduce the effects of rapid change in ambient illumination. However the availability of data on the efficacy of these lenses with regard to vision enhancement and therapeusis is limited.

The results of a poll of practitioners using CPF 550 lenses were reported in "Rehabilitative Optometry" (1983) and were mixed but generally positive. The filters were used by patients with RP, albinism, SMD, cataract, diabetic retinopathy and other retinal degenerations. The trend was for an awareness of increased contrast and comfort over other filter systems whether or not acuity improved. The reports of increased peripheral fields by some patients could not be substantiated objectively. Some practitioners felt that the expense was not justified in view of the minimal visual improvements and the other limitations encountered with red lenses.

Lynch and Brilliant (1984) compared the CPF 550 with a 20% neutral density filter on RP patients and found that the majority showed an increase in Snellen acuity (but only by 1/4 of a line) and contrast sensitivity and adaptation time were unaltered. The subjective feeling of decreased sensitivity to glare was the most positive finding particularly in those with posterior subcapsular cataracts. Megla (1983) of Corning Glass reported the subjective responses in questionnaires and testimonial letters that "most people" after getting used to the colour variation notice greater eye comfort, less strain from glare, contrast enhancement and a feeling of improved acuity and shorter adaptation times.

THERAPEUTIC EFFECTS:

"Red" lenses such as the CPF series were developed primarily for the retardation of retinal pigmentary degenerative disease such as retinitis pigmentosa (RP). There is some confusion in the literatuare over this point. Adrian and Schmidt (1975) described the management of RP with a specifically designed red filter whereas Lederer (1979) advocated the use of a blue lens for the same type of condition. Berson (1980) in order to test the hypothesis that light deprivation helps to retain visual function in RP, fitted one eye of each patient with an opaque scleral contact lens and compared the progression of the disease in the occluded eyes with that in their fellow eyes. After five years there was no difference in the rates of progression, supporting the findings in light deprivation studies of pigmented rodents with retinal degenerations (LaVail, 1980). However, while emphasizing that there is no evidence that any type of sunglass retards the progression of RP, Berson advocated the use of "dark" sunglasses by RP patients when outdoors since sudden increases in illumination may aggravate the course of the disease. Based on many years of management of RP patients using CPF and other filters, Woo et al (1981, 1984) have been unable to confirm any definite therapeutic (retarding) value for any lens, despite subjective improvements in comfort and vision. Thus the therapeutic effect of CPF lenses has not been confirmed, and well controlled clinical trials have yet to be completed.

TABLE 1

Luminous transmittance and color of CPF lenses

	Darkened State	Lightened State	Color (Lightened)	Color (Darkened)
CPF511	16%	47%	Yellow-amber	Beige
CPF527	12%	37%	Orange-amber	Brown
CPF550	5%	21%	Reddish-amber	Maroon

FIGURE LEGENDS

Fig. 1 Photobiological subdivisions of the optical spectrum. Borders may vary 5 to 10 nm in schemes adapted by different scientific bodies and investigators.

Fig. 2 Total and direct transmittance of the ocular media (after Boettner and Wolter, 1962).

Fig. 3 Ultraviolet action spectra for injury to the cornea and lens in three species (rabbit, monkey and man) as derived by three independent research groups. The similarities are striking when the differences in experimental design and the difficulties encountered with UV spectroradiometry are considered.

Fig. 4 Anterior subcapsular opacities produced in the lens by acute irradiation with UV-B.

Fig. 5 Transmittance curves comparing solid glass, coated glass and dyed plastic brown tints. Although visually similar, transmittance in the visible spectrum and protective properties against UV and IR are quite different.

Fig. 6 Transmittance curves for light and darkened state CPF 550 filters.

REFERENCES

1) Adrian W., Schmidt I. Photic damage in retinitis pigmentosa and a suggestion for a protective device. (1975) J. Am Optom Assoc. 46:380-6.

2) Anonymous. Panel Review-CPF 550 lenses. Rehab Optom (1983) 1(2):15.

3) Bachem A. Ophthalmic ultraviolet action spectra. Am J Ophthalmol (1956) 41:969-75.

4) Berson EL. Light deprivation and retinitis pigmentosa. Vis Research (1980) 20:1179-84.

5) Bier N. Filter therapy in retinitis pigmentosa. Ophthal Opt. (1983) 43(12):392-5.

6) Boettner EA, Wolter JR. Transmission of the ocular media. Invest Ophthalmol (1962) 1(6):766-83.

7) Borgwardt B, Fisherman GA, Vander Meulen D. Spectral transmission characteristics of tinted lenses. Arch Ophthalmol (1981) 99(2):293-7.

8) Clark BAJ. Color in sunglass lenses. Am J Optom Arch Am Acad Optom 46(11):825-40.

9) Chou BR, Cullen AP, Egan DJ. Spectral transmittance of contact lens materials. Inter Contact Lens Clinic (1984) 11(2):106-15

10) Chou BR, Cullen AP. Spectral transmittance of selected tinted ophthalmic lenses. Can J Optom. (1983) 45(4):192-8.

11) Chou BR, Cullen AP. Spectral characteristics of sports and occupational tinted lenses. Can J Optom. (1984) (submitted for publication).

12) Chou BR, Cullen AP. Optical radiation protection by non-prescription sunglasses. (1984b) (In preparation).

13) Clear AS, Chirambo MC, Hutt SR. Solar keratosis, pterygium and squamous cell carcinoma in Malawi. Br J Ophthalmol. (1979) 63:102-9.

14) Cogan DG, Kinsey VE. Action spectrum of keratitis produced by ultraviolet radiation. Arch Ophthalmol. (1946) 35:670-7.

15) Cullen AP. Ultraviolet induced lysosome activity in corneal epithelium. Albrecht von Graefes Arch Klin Exp Ophthalmol. (1980) 214:107-18.

(16) Cullen AP, Chou BR, Hall MG, Jany SE. Ultraviolet-B damages corneal endothelium. Am J Optom Physiol Opt. (1984) 61(7):473-8.

17) Cullen AP, Chou BR. Optical radiation protection for operators of light-curing units in dental practice. (1984) (In preparation).

18) Dain SJ, Nasser G, Ramshaw P, Russel GK, Vercoe GJ. Technical note: Guide to the transmittance properties of some ophthalmic lenses. Aust J Optom. (1981) 65(4):165-8.

19) Duke-Elder S. System of Ophthalmology vol. XIV, Part II. Non-mechanical Injuries. London: Henry Kimpton, (1972) 837-1004.

20) Ebber RW, Sears D. Ocular effects of 325 nm ultraviolet laser. Am J Optom Physiol Opt (1975) 52:216-23.

21) Garner LF. The transmission properties of some commercial ophthalmic tinted lenses. Aust J Optom (1973) 56(7):254-61.

22) Garner LF. A guide to the selection of ophthalmic tinted lenses. Aust J Optom. (1974) 57:346-50.

23) Geeraets WJ, Williams RC, Chen C, Ham WT, Guerry D III, Schmidt FH. The loss of light energy in the retina and choroid. Arch Ophthalmol. (1960) 64:606-15.

24) Egan DJ. The application of selected broadband red filters for red-green deficiencies. Can J Optom. (1982) 44(1):50-7.

25) Ham WT Jr, Muller HA, Ruffolo JJ Jr., Clark AM. Sensitivity of the retina to radiation damage as a function of wavelength. Photochem Photobiol. (1979) 29:735-43.

26) Ham WT Jr., Mueller HA, Ruffolo JJ Jr., Guerry D III. Solar retinopathy as a function of wavelength: Its significance for protective eyewear. In Williams TP, Baker BN (Eds). The Effects of Constant Light on Visual Processes. New York: Plenum Press (1980) 329-46.

27) Ham WT Jr, Mueller HA, Ruffolo JJ Jr., Guerry D III, Guerry RK. Action spectrum for retinal injury from near-ultraviolet radiation in the aphakic monkey. Am J Ophthalmol (1982) 93:299-306.

28) Harwerth RS, Sperling HG. Effects of intense visible radiation on the increment threshold spectral sensitivity of the Rhesus monkey eye. Vision Res (1975) 15:1193-204.

30) Hoeft WW, Hughes MK. A comparative study of low vision patients: Their ocular disease and preference for one specific series of light transmission filters. Am J Optom Physiol Opt (1981) 58(10):841-5.

31) Hollows F, Morgan D. Cataract-the ultraviolet risk factor. Lancet (1981) Dec. 5:1249-51.

32) Kinney JAS, Schlichting CJ, Neri DF, Kindness NS. US Naval Submarine Medical Research Laboratory. Report No. 941 (1980).

33) Kors K, Peter HB. Absorption characteristics of selected commercially available ophthalmic lenses. Am J Optom Arch Am Acad Optom (1972) 49(9):727-35.

34) Laur AR. Further studies of the effect of certain transmission filters on visual acuity with and without glare. Highway Research Board Bull (1951) 43:45-51.

35) LaVail MM. Interaction of environmental light and eye pigmentation. Vis Res. (1980) 20:1173-7.

36) Lawwill T, Crocket S, Currier G. Retinal damage secondary to chronic light exposure thresholds and mechanisms. Doc Ophthalmol. (1977) 44(2):379-402.

37) Lederer J. New lens combats retinitis pigmentosa. Optom Mon. (1979) 70:681.

38) Lerman S. Lens proteins and fluorescence. Israel J Med Sci (1972) 8:1583-9.

39) Lynch DM, Brilliant R. An evaluation of the Corning CPF550 lens. Optom Mon. (1984) 75(1):36-42.

40) MacKeen D, Fine S, Fine BS. Production of cataracts in rabbits with an ultraviolet laser. Ophthalmic Res. (1973) 5:317-24.

41) Megla GK. Selectively absorbing glasses for the potential prevention of ocular disorders. Appl Opt. (1983) 22(8):1216-20.

42) Neumueller J. Variations in visual acuity with various absorption lenses. Am J Optom Arch Am Acad Optom (1936) 13(2):61-8.

43) Pitts DG, Cullen AP, Hacker PD. Ocular effects of ultraviolet radiation from 295 to 365 nm. Invest Ophthalmol (1977) 16(10):932-9.

44) Pitts DG, Cullen AP. Determination of infrared radiation levels for acute ocular cataractogenesis. Albrect von Graefes Arch Klin Exp Ophthalmol (1981) 217:285-97.

45) Pitts DG, Bergmanson JPG, Chu LW-F. Rabbit eye exposure to broad-spectrum fluorescent light. Acta Ophthalmol Suppl (1983) 159:54.

46) Reid AM. A comparative trial of goggles, multipurpose, in the middle east. UK Ministry of Supply, Clothing and Stores Experimental Establishment, Report No. 76. (1955).

47) Spector A, Roy D, Stauffer J. Isolation and characterization of an age depicted polypeptide from human lens and nontryptophan fluorescence. Exp Eye Res. (1975) 21:9-24.

48) Yap M. The effect of a yellow filter on contrast sensitivity. Ophthal Physiol Opt. (1984) 4(3):227-32.

49) Weale RA. The age variations of senile cataract in various parts of the world. Br J Ophthalmol (1982) 66:31-4.

50) Woo GC. Hackner AJ. An update on therapies for retinitis pigmentosa. Can J Optom (1981) 43(1):46-8.

51) Woo GC, Strong G. Personal Communication (1984).

52) Wyszecki G. Theoretical investigation of colored lenses for snow goggles. J Opt Soc Am (1956) 46:1071-4.

53) Zigman S, Schultz B, Yulo T, Grover D. Effects of near-UV irradiation on lens and aqueous humor proteins. Israel J Med Sci (1972) 8:1590-5.

54) Zigman S, Griess G, Yulo T, Schultz J. Ocular protein alterations by near UV light. Exp Eye Res (1973) 15:255-64.

55) Zigman S, Datiles M, Torczynski G. Sunlight and human cataracts. Invest Ophthalmol (1979) 18:462-67.

56) Zuclich JA, Connolly JS. Ocular damage induced by near-ultraviolet laser radiation. Invest Ophthalmol (1976) 15(9):760-4.

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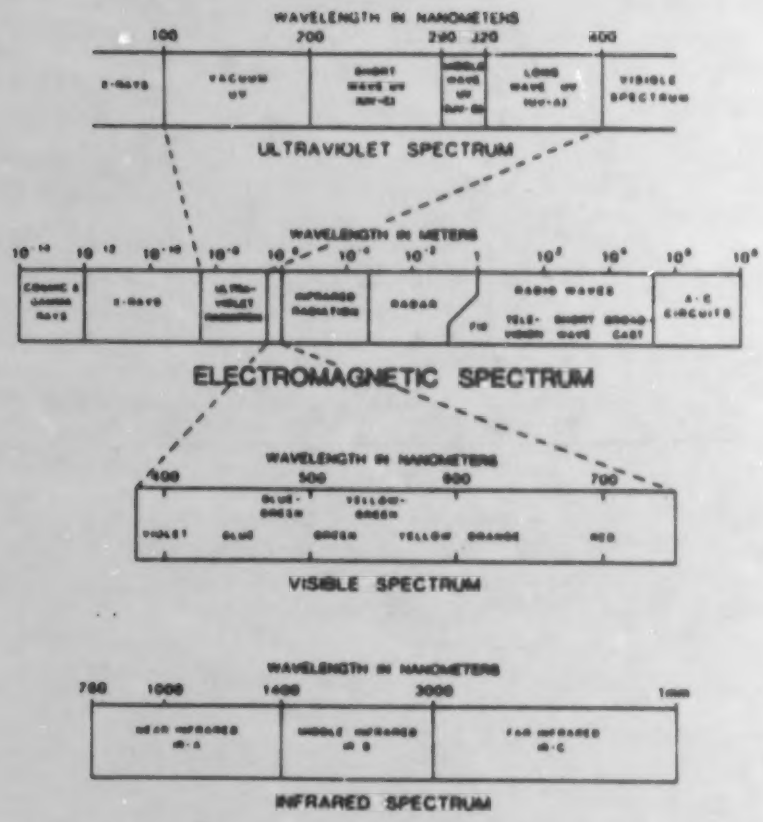

Figure 1.

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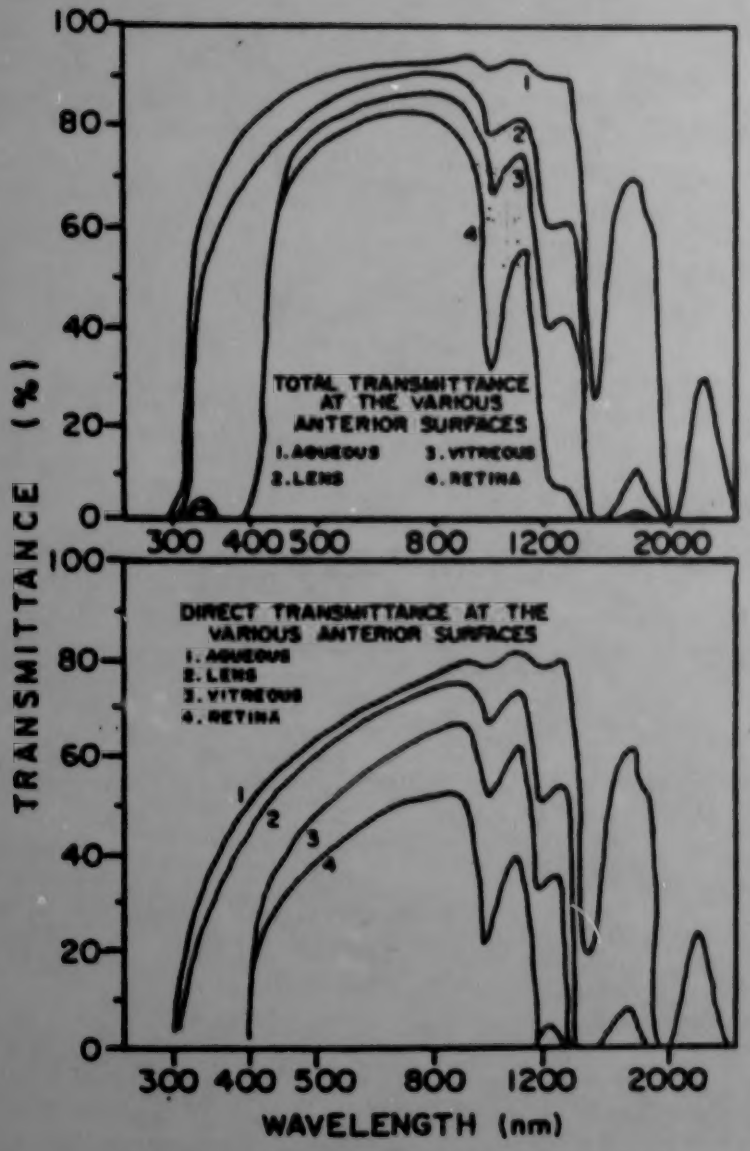
TRANSMITTANCE (%)
100
80
60
40
20
0
TOTAL TRANSMITTANCE AT THE VARIOUS ANTERIOR SURFACES
1. AQUEOUS
2. LENS
3. VITREOUS
4. RETINA
300 400 500 800 1200 2000
DIRECT TRANSMITTANCE AT THE VARIOUS ANTERIOR SURFACES
1. AQUEOUS
2. LENS
3. VITREOUS
4. RETINA
WAVELENGTH (nm)

Figure 2.

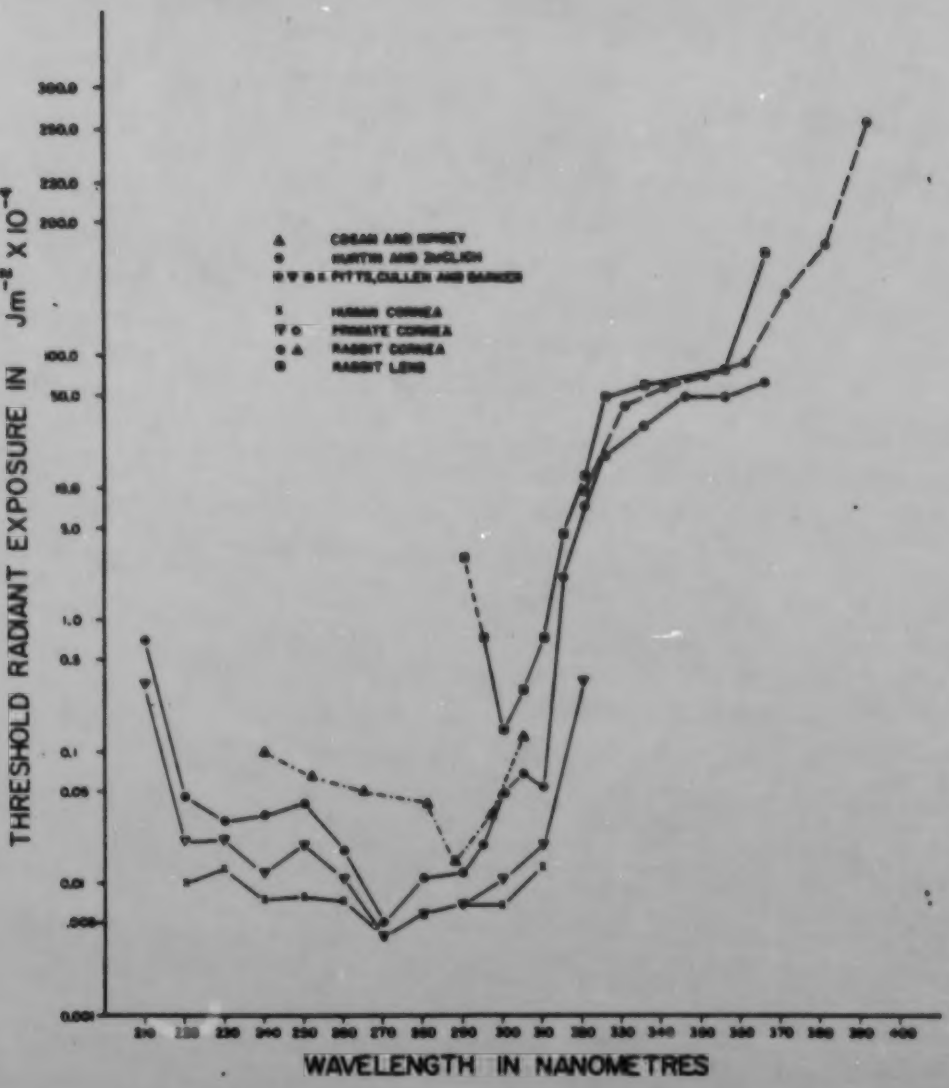

Figure 3.

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Figure 4.

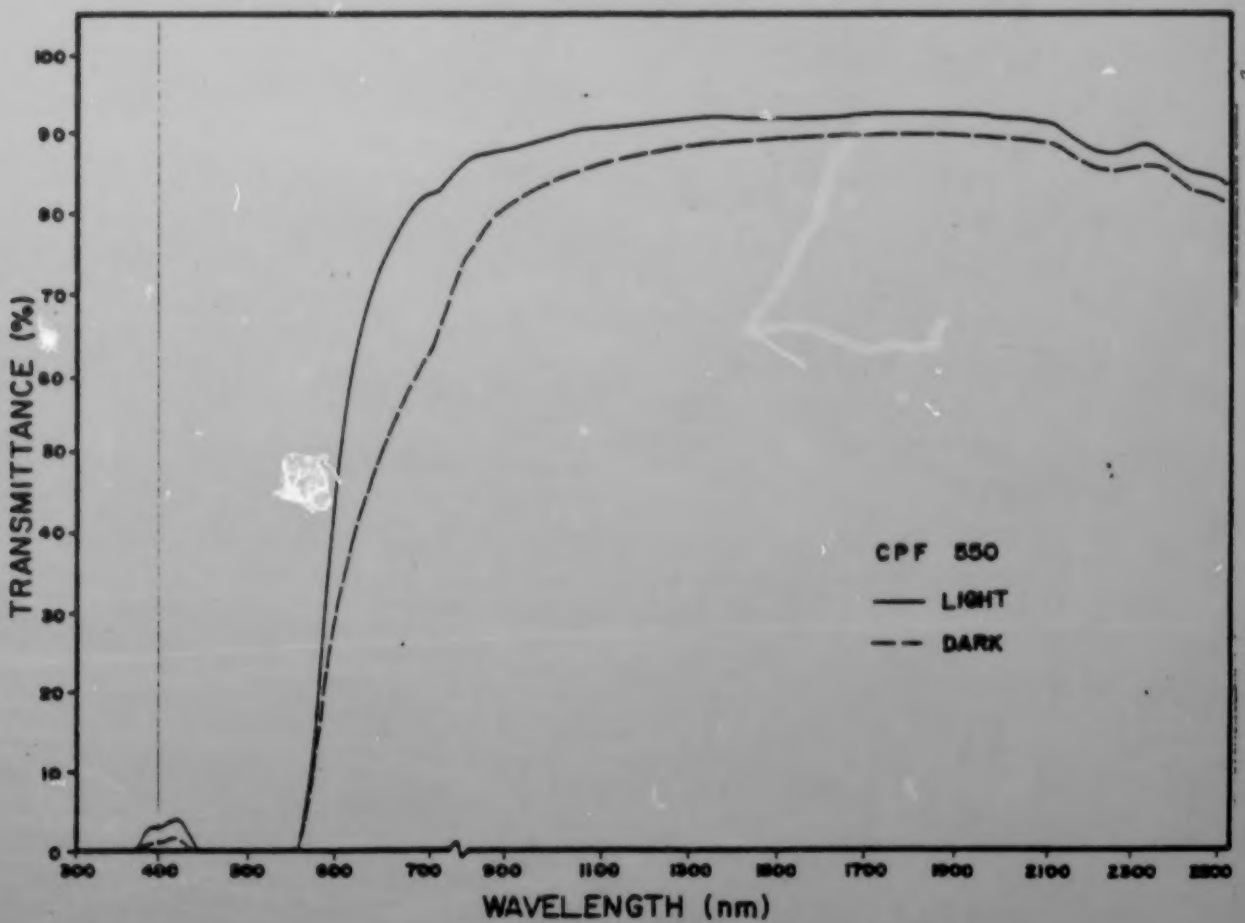

Figure 5.

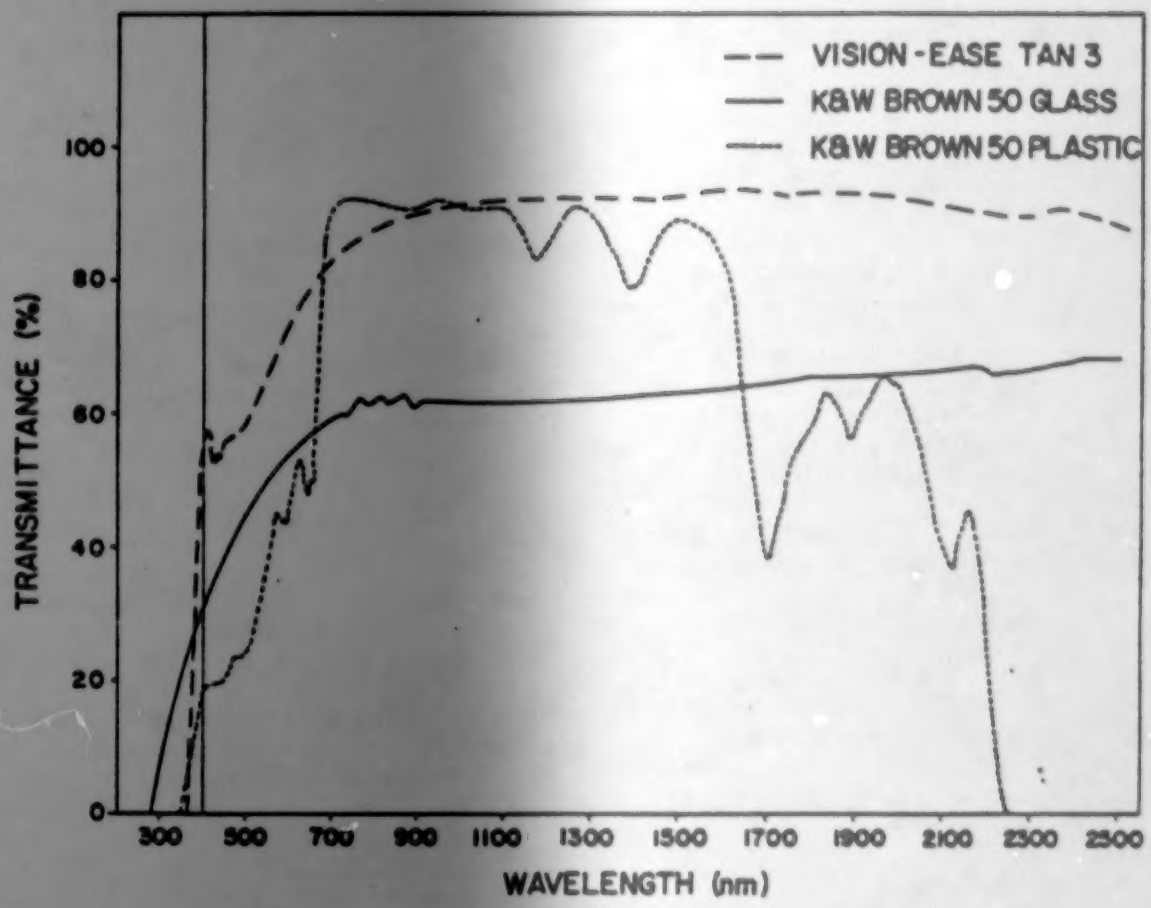
VISION-EASE TAN 3
K&W BROWN 50 GLASS
K&W BROWN 50 PLASTIC
TRANSMITTANCE (%)
0
20
40
60
80
100
300
500
700
900
1100
1300
1500
1700
1900
2100
2300
2500
WAVELENGTH (nm)

Figure 6.

DIAGNOSTIC CLUES IN THE PHYSICAL APPEARANCE OF THE VISUALLY IMPAIRED CHILD

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INTRODUCTION:

When visual impairment is congenital or acquired, complete or partial, loss of sight results in certain neurological changes. Visually impaired children exhibit many meaningful physical signs which are often not fully understood by professionals who care for them. The past history is expressed by their eye and head movements, posture, gait, mannerisms, physical build and behavior. The purpose of my presentation is to discuss these physical signs and to make them more meaningful.

Sensory Nystagmus (SN):

My comments are based on a prospective study of 347 visually impaired children (1). There are several types of nystagmus, each reflecting various neurological disorders. Only sensory nystagmus (SN) due to visual deprivation is discussed here. Sensory nystagmus is defined as conjugate (both eyes moving in the same direction) oscillations (tremor) of the eyes, associated with visual loss and elicited by attempts at fixations. The majority of visually impaired children exhibit SN.

Children with SN are either born with a significant visual loss or acquire it under the age of one year. Those who suddenly become blind after the age of one year do not develop it. (With gradual loss of sight it may be difficult to determine accurately the onset of significant visual impairment). In North America the majority of visually impaired children are born with their visual loss, which explains why most of these children exhibit SN. These oscillations elicited by fixation (looking at things) are due to unknown neuronal changes in the cortical centres of fixation, located in the occipital-parietal lobes. They are caused by significant visual deprivation during the critical period of the first year of life.

Sustained (prolonged) SN indicates the presence of useful vision, no matter how minimal. It is absent in totally blind children, who tend to exhibit slowly drifting, roving eye movements. Visual acuity of 20/70 or better is generally not associated with SN unless there was a significant uncorrected-refractory error during the first year of life. Therefore, the vision was worst during the first year of life in these children. The presence and degree of SN are determined by the visual acuity during this critical period.

Sustained SN is the hallmark of ocular and anterior visual pathway disorders. It is not seen in children with cortical visual impairment.

Probably all legally blind children have roving eye movements in the newborn period. Infants with useful sight gradually develop SN and later the roving subsides. Sensory nystagmus is not seen at birth. Children with 20/200 acuity frequently begin to exhibit nystagmus between 1 1/2 and 2 months combined with roving until 4 to 6 months of age. Children with worse vision may develop SN between 6 and 8 months and lose roving after 1 year of age. Thus, earlier onset nystagmus implies better visual acuity. Congenital nystagmus, therefore, is not a satisfactory term (congenital means 'since birth'). In fact nystagmus which is present at birth is due to other neurological disorders. Sensory nystagmus is the result and the sign and not the cause of visual impairment. Sensory nystagmus is produced by central and not peripheral visual deprivation. Finally, sensory nystagmus is extremely variable and it is influenced by many dynamic factors.

Oculomotor Apraxia and Associated Head Movements:

Normal infants exhibit marked oculomotor apraxia (inco-ordination) but their eye movements improve. Children with congenital or acquired visual impairment under the age of one year retain their oculomotor apraxia. The degree of apraxia tends to reflect visual acuity. Those with an acuity of 20/100 or better generally follow moving objects with good fluency and minimal associated head movements. Their voluntary upgaze is normal. Fixation is strong and they keep their heads erect. When vision in the better eye is close to 20/200, the associated head movements during pursuit and looking on command are noticeably increased and the eye movements become jerky and clumsy. These children still keep their heads erect, but their voluntary upgaze may be limited and fast passive head movements can dislodge their fixation. When the vision is severely impaired, the oculomotor apraxia is also more severe. These children lack fluent eye movements and they are frequently unable to look up

voluntarily. Even slow passive head movements break their fixation and when not actively looking at something their heads often hang down. In pursuit and looking on command, they move mainly their heads, rather than their eyes. With total loss of vision there is no pursuit and the voluntary eye movements are absent. These individuals keep their heads erect only when taught to do so. Oculomotor apraxia can be improved by specific eye exercises, and it is also influenced by the individual's visual efficiency. Some bright children tend to use their residual vision surprisingly more efficiently than others and with less oculomotor apraxia.

The restriction of voluntary upgaze in visually impaired children is simply a disuse phenomenon, because with diminishing visual acuity they look up less and less frequently. A child who can see only one foot away sees nothing if he looks up, but he sees much more when he looks sideways or down.

Head Position:

Visual contact with the environment is the main stimulus for individuals to keep their heads erect. Thus, children with severe visual loss tend to hold their heads erect only when something comes within the limits of their vision. Of course, parents and professionals encourage the erect head position because it is socially more acceptable.

Cortical Visual Impairment:

There are many children who are visually impaired, even though their ophthalmological examination is normal or close to normal. They tend to be multihandicapped, with delayed developed, epilepsy, cerebral palsy or hydrocephalus. Most of these children have cortical visual loss. My comments are based on a study of 50 children with the diagnosis of permanent cortical visual impairment (2).

In the past, only the most severe cases of cortical visual impairment(CVI) were diagnosed. The reason for this was that the accepted definition of CVI was too restrictive and also incorrect. Accordingly, it was only diagnosed when the visual loss was complete and the pupillary light response, fundus and eye movements were normal. Our findings, however, indicate that children with permanent CVI have residual sight, their eye examinations more often than not are abnormal and in addition they frequently have abnormal eye movements.

Let us examine a hypothetical patient. We are confronted with a 6 year old multihandicapped child, who has been visually impaired since birth. He seems to look at people or objects momentarily, but shows no visual attentiveness, even though he understands us, and even speaks a little. Ophthalmological examination reveals minimal optic nerve atrophy, but no evidence of nystagmus. However, the ocular findings do not fully explain his severe visual loss. He cannot follow visually and will not look at objects on command. Although most of the time his eye movements appear to be smooth, occasionally they are jerky. Our diagnosis is quick. Since this congenitally visually impaired child does not have sustained sensory nystagmus, his visual loss is not due to ocular causes and there must be profound damage to the visual cortex or post-geniculate visual pathways. Indeed, subsequent neurological investigations (which include electroencephalograms, CT scan, Visual Evoked Potential and Visual Evoked Potential mapping studies) reveal the correct diagnosis of permanent CVI.

Visual Evoked Potential mapping is a useful new technique (3). It is not only more reliable than visual evoked potential studies, but this electrophysiological test reveals different types of cortical visual impairment and confirms the impression that permanent CVI is much more common than previously thought. Many of these children have additional defects, but the funduscopic findings fail to explain the cause of poor vision. They do not "appear blind" because they lack sustained nystagmus, roving and poorly co-ordinated eye movements. The visual function is extremely variable. At times they can recognize familiar objects in one environment, but not in another. When objects are named, they seem to be able to spot them more easily. They frequently supplement their vision with touch, but when they reach for objects they may look away. Some children are able to identify only the colour of objects, but with touch they can identify them correctly. In many children with residual sight, psychological testing shows severe to profound visual perception difficulties.

<u>Visual Self-Stimulation:</u>

Many children with visual impairment exhibit one or more types of self stimulating behavior, such as rocking, head rolling, body swaying, twirling, tapping, hand flapping, eye pressing, gazing at light, rapid blinking, waving their fingers between their eyes and bright light, hyperventilation, sniffing and a great variety of other stereotyped mannerisms. Eye pressing, light gazing, rapid forced blinking and finger waving involve the visual system

and are more or less restricted to visually impaired children. Eye pressing is the most common. My comments on visual self-stimulation are based on a study of approximately 800 visually impaired children (4).

Eye pressing is not the same as eye rubbing in children who are tired, sleepy or who have sore, itchy eyes. With variable frequency, duration and strength, prolonged pressure is exerted on the globes and peri-orbital area in an individual style. The children may use thumbs, fingers, knuckles or fists. Pressure over the eyes generates action potentials in the retina, which travel to the visual cortex and result in sparks of light being seen.

What does eye pressing mean? First, these children are visually impaired and the visual loss is severe but not total. Furthermore the visual pathways must be intact, because patients with totally destroyed eyes, with optic nerve atrophy or cortical blindness do not exhibit this mannerism. Children with congenital amaurosis of Leber and some other retinopathies, such as retrolental fibroplasia, press with such striking intensity that this alone suggests the diagnosis of a retinal disorder. Only children with congenital or early visual loss use visual self-stimulation.

It is well known that children with additional handicaps, especially mental retardation and psychiatric disorders, tend to have more blind mannerisms of all kinds. These mannerisms are also more frequent when the children are tired, anxious, bored or sleepy. Experienced educators of the blind have been able to recognize the eye pressors at a glance, simply because the globes appear to be sunken and the periorbital skin is darkened. Indeed, radiographs of the orbits and CT scans of the globes in selected blind children have shown that prolonged eye pressing can lead to expansion of the orbit and atrophy of the fat and soft tissues. The globes may become so sunken that air pockets are created between the orbital rim and the over-stretched soft tissue of the globe.

There is an innate need to explore and learn as the brain demands input from the senses. Children with moderately impaired vision or unilateral blindness, receive adequate visual information, but when there is little useful sight, the visual cortex and other regions of the brain require additional input, even if it is not meaningful. However, in total blindness, the visual pathways are destroyed and visual self-stimulation does not occur. At least to begin with, visual self stimalation must be determined by a fluctuating balance between demand and the adequacy of meaningful visual input. Later it can become a habit. Other self-stimulating mannerisms can also be similarly explained on a neurophysiological basis.

In conclusion, eye pressing is influenced by the onset of visual impairment, age, the degree and quality of residual vision, the presence of additional handicaps and the types of activities in which the children are involved.

Hypotonia, Gait and Posture in Visually Impaired Children:

Hypotonia is a looseness of muscles and ligaments. It is diagnosed by palpating the patient's muscles, by feeling the resistance of limbs on passive manipulation and by various other manoeuvres. My comments are based on a study of 197 visually impaired children (5).

It has been noted that many visually impaired children are "floppy", even with intact nervous systems. Congenitially blind children with light perception, or less, are especially pre-disposed to hypotonia. Children with good partial sight and with acquired visual loss after the first year of life are much less likely to develop reduced body tone. The aetiology of blindness is not related to the presence or absence of hypotonia. However, it is closely associated with a delay in early motor development. It is well known that blind infants tend to be quiet, passive and require active encouragement to sit, stand, creep and walk. Young children with severe visual loss do not acquire skills through accidental learning as do the sighted. To the blind, even simple motor tasks, such as shaking, pushing, pulling, jumping or kicking, have to be taught. The delay of early motor development in the hypotonic, congenitally blind child is usually explained by the lack of appropriate opportunities for mastering these early motor skills. These children usually have a flattened skull posteriorly, indicating excessive time spent in the supine position. They tend to be poorly co-ordinated and to walk with plano-valgus feet on an insecure, wide base. Hypotonia, poor co-ordination and gait can be improved by adequate and appropriate physical activities, when introduced especially during the first two to three years of life. Otherwise these children remain poorly co-ordinated and later experience difficulties with their mobility and orientation skills.

The hands of neglected blind are often maintained in an infantile position and seem useless and small. Many of these children may not even know how to use touch to compensate for their visual loss. The feet of blind children who have not ambulated are deformed, and not suitable for weight bearing.

There are a vast number of other clinical clues which have not been discussed. Many of them reach us at a subconscious level, but we receive constant messages when we observe

visually impaired children, how they move, talk, behave and think. With experience, those who work with blind children can understand their past history. It is all there, we just have to read it.

Lastly, in our discussions of sensory nystagmus, ocular motor apraxia, visual self-stimulation, hypotonia and co-ordination difficulties, it has become apparent that the first one to two years of life are crucially important for children with congenital visual impairment. This critical period is explained by the extreme pliability of the brain during the early years of life. As a result it is clear that the habilitation of visually impaired children must begin immediately after the diagnosis of visual loss.

REFERENCES:

(1) Jan, J.E., Farrell, K., Wong, P.K., McCormick, A.Q.,: Eye and head movements in visually impaired children. (Submitted to Developmental Medicine and Child Neurology).

(2) Whiting, S., Jan, J.E., Wong, P.K., Farrell, K., Flodmark, O., McCormick, A.Q.,: Permanent cortical visual impairment in children. (Developmental Medicine and Child Neurology in press)

(3) Wong, P.K.H., Jan, J.E., Farrell, K., Flodmark, O., Whiting, S.: Topographical visual evoked potential mapping in children with permanent cortical visual impairment. (Not submitted for publishing yet).

(4) Jan, J.E., Freeman, R.D.., McCormick, A.Q., Scott, E.P., Robertson, W.D., Newman, D.E.,: Eye-Pressing by visually impaired children. Developmental Medicine and Child Neurology, 1983. 25: 755 - 762.

(5) Jan, J.E., Robinson, G.C., Scott, E., Kinnis, C.: Hypotonia in the blind child. Developmental Medicine and Child Neurology, 1975. 17: 35 - 40.

VARIOUS TOPICS IN PAEDIATRIC OPHTHALMOLOGY: QUESTIONS AND ANSWERS

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Dr. McCormick: First I would like to talk about retrolental fibroplasia, (RLF), a disorder that has been around now for 40 years and which we have not yet learned to conquer. As we more successfully treat premature babies, we expect to see more and more blindness but the Canadian experience does not really support that. I have looked at the registration with the CNIB from 1940 up to the present time. The diagnosis of RLF is made by a wide variety of physicians and there may be errors. But on the other hand, over the past couple of decades we have had increasingly sophisticated methods of examining premature babies and the number of paediatric ophthalmologists who are interested in this disorder also increased. Therefore I really do think this is an honest expression of the incidence we see in this country.

In the early 1950's we had an enormous epidemic of RLF. It has been estimated that in North America alone about 10,000 babies might have become blind during that time. Then with the restriction of oxygen in the late 1950's the incidence of this ocular disorder fell quite dramatically, but we have had a persisting problem since and thus our experience here. It is with a real feeling of sadness that I recognize that in 1982, 14 infants with RLF were registered in Canada, half of them from British Columbia. Still there does not seem to be a steady increase.

Question: All over the world an increase of retrolental fibroplasia has been reported. Are you saying that this is not so in British Columbia?

Dr. McCormick: True, there are some years when it is worse, but as a general rule I do not think there is an increase of RLF in B.C.

Dr. Hoyt: Well, there is this controversy about whether the RLF is increasing. John Flynn feels in Miami that it very much is. Now, he is in a charity hospital without as good prenatal care, perhaps, as you have. The statistics in Seattle are like yours. They have not changed in two decades. We have not seen a great increase in San Francisco at the University, although in Northern California area we probably have.

Question: In California, where I work, we have seen a significant increase of RLF.

Dr. Hoyt: One of the problems in the United States is the failure to establish prospective Registries of blind children, so we end up with anecdotal data. If, indeed RLF has increased, and there are places where it has, perhaps, it is related to the survival of smaller babies. 1500 gm babies with RLF are almost unheard of now. These babies weigh about 700 to 900 gm, they are often twins, severely sick, with lots of other problems. However, there is another factor. RLF can be minimal to devastating, and I think those of you at the end of the pipeline, taking care of these kids, you are seeing more of the bad cases. That does not mean increased incidence. It only means that when it happens, it goes right on and ends up being bad. This is our own experience.

Question: In Northern Saskatchewan alone last year I registered 5 RLF infants, which is a marked change from before.

Dr. McCormick: One of the problems is that we are dealing with very small numbers. I was depressed in 1982 when we had 7 blind babies in our Nursery. But in 1983 we only had 1 and in 1984, none. So I do not think that when a single person encounters a bad year, or three bad years, this will necessarily mean that we have a national epidemic.

Question: Dr. McCormick, are there a comparable number of premature infants each year?

Dr. McCormick: Yes, there are comparable numbers each year. Although there is a general trend upward in terms of our nursery population and also survival of small babies.

Dr. Hill: Just to underline the question, the numbers of very small babies surviving are greater and greater every year, so you would have to expect, on the basis of weight alone, to be seeing more and more cases of RLF.

Dr. Hoyt: Litigation in the United States I think has made RLF, perhaps, artificially more apparent. RLF represents 10% of the total malpractice bill for the University of California per year. Now, that doesn't take many settlements. Blind children, with a long life expectancy usually receive huge settlements. Also, many families of children with RLF are flying off to Boston and Tennessee and so forth for vitrectromy, so there may be some additional factors that have made RLF more apparent than it was before.

Question: Can you enlarge on vitrectomy, which appears to be quite controversial?

Dr. Hoyt: Yes, it is controversial. Vitrectomy is for children with severe or complete, bilateral retinal detachment. All the vitreous and scarred material is removed and the retina is re-attached. Nobody is proposing re-attachment of the macula in order to get reading vision. They are trying to restore enough peripheral retina to help the child to become independently ambulatory. Perhaps between 30% and 50% of the children who have the operation have an anatomical success, so the retina can be seen to be attached in places. However, the number of children who functionally show recovery is much smaller. In the small series at our University, 20% to 25% of the kids show some evidence of useful peripheral retinal function, which may help them in terms of their ambulation. They are all young, and have only been followed for the last couple of years. Unfortunately, many families have been swept up into the notion that it can only be done in Boston or Memphis and they have sold their homes and flown off for a technology that is readily available in every major city.

Question: At what age are you doing vitrectomies?

Dr. Hoyt: Well, that is also controversial, but the general consensus is that one must wait until the exudative part of the disease goes away. I do not think anybody is keen to do it until the child is at least 3 to 4 months old. There are a number of factors to consider. How long the retina has been detached, the blood supply, the degree of anatomic destruction.

Question: Is there a relationship between prematurity, brain development and visual loss?

Dr. Hoyt: Because the infant is premature, it does not automatically mean brain damage. However, an insult like hypoxia causes a different type of damage to the brain of a premature than to that of a full term infant. The damage to the visual pathways is also different. There are some paradoxical reasons why prematures might do better than full term babies. For example, myelinization of the visual pathway is enhanced by light. It appears that the formation of the normal sheaths around the visual pathway (myelinization) is faster in the premature than in the full term baby.

Question: What kind of instrument do you use for vitrectomy?

Dr. Hoyt: If you just mentally close your eyes and imagine a rotor router and reduce it to the size of your little finger, or less, that is a vitrectomy instrument. Essentially the instrument has a sharp cutting edge inside a power driven cylinder and the edge can be moved up and down so that you can shear scar tissue and gelatinous tissue, like the vitreous. The instrument is placed into the eye of a child with retrolental fibroplasia. It then cuts away all the vitreous, which is in scar tissue holding the retina. Children with RLF are much worse off than adults with retinal detachments. In adults, fluid just percolates through a hole and pushes the retina off. But kids with RLF have marked scars in front of their retinas, which have to be removed before the retina can be re-attached. So the vitrectomy instrument is put in, the scar tissue is cut away and then depending on who does the surgery, an encircling buckle is placed around the eye. It then squishes down onto the retina. It is a relatively hazardous technique. That is why it is essentially the people who have done lots of vitrectomy surgery in other situations who are doing it.

Question: Can you discuss lens implant in children?

Dr. Hoyt: Well, this issue is near and dear to my heart, since I spent a few years of my life trying to figure out how to take care of kids with cataracts. One of the problems is that a child is not a static biologic system. The eye goes through a lot of changes in the first year of life. It elongates 50%, the cornea flattens about 40% and so the power of the eye changes. If one operates in the first few weeks of life, the power

of contact lens or glass, or whatever is used to correct the loss of lens will have to be changed radically. They might have a + 30 dioptre lens at 2 weeks of age but require a + 18 at one year of age. Fixed intra-ocular lenses or implants are not used in children because there is not any way to change the power. There have been attempts to use them at a later date and there is a report of this from Israel. If a fixed intra-ocular lens is placed in a baby, he ends up wearing a myopic contact lens when he is a year old. That is not to say that the fitting of contact lenses in babies with cataracts is a great routine. They lose 8 to 10 a year. Most insurahce programs in California will not pay for them after the first lens or two. The Crippled Children's Service in California has already declared contact lenses in aphakic children an experimental procedure, so that parents often are stuck with $1,000 or $2,000 bills a year. There is a real need for a reliable and inexpensive way to correct these children, and I do not see an immediate solution to the problem.

Dr. McCormick: I would just make a comment. Mother Nature never intended that the human eye should have a plastic lens, and last for 75 years. If a 75 year old has a cataract, I would say, "By all means get a plastic lens", but for a child this is a different matter, and very dangerous.

Dr. Hoyt: By nature, intra-ocular lenses compromise the drainage of the eye. When an eye has glaucoma, one would especially like to avoid an intra-ocular lens, because that is a dangerous situation. There are some other alternatives. The people in New Orleans are using epikeraphakic grafts. They take a piece of corneal tissue, they put it on a lathe and they cut it into what looks like a human contact lens. Then they sew it on the baby's eye, as a contact lens graft. Glaucoma in children with cataracts is still a major problem. 5% of all kids with cataracts will develop glaucoma at some time and it makes their management much, much harder.

Question: This morning Dr. Carruthers was speaking about albinism and referred to an abnormal decussation in certain cases. I am just wondering how this might affect nystagmus?

Dr. Hoyt: Those of you who are Siamese cat lovers know that if you have a Siamese cat which is not cross eyed, and does not have nystagmus, you have been had. It is not a full bred Siamese cat. And so the albino model has been

the model, in fact, for studying strabismus and nystagmus. There are patients who are not albinotic, but have congenital motor nystagmus and their visual evoked potentials are exactly that of an albino, suggesting that this abnormal decussation is, in fact, the underlying pathophysiology of their nystagmus. The current thinking, is that the decussation abnormality is in fact part and parcel of what produces the abnormal ocular motor system in the albino. It is a very complicated system. If you think about it for a second, if you had all this information crossing from the right eye to the left brain and all from the left eye to the right brain, you should have visual field defects, but they do not. So there is a supranuclear adaptation. There are a bunch of adaptations beyond the lateral geniculate body. There have also been some preliminary studies to show that the decussation of the auditory pathway in albinos is abnormal, and yet they have no clinical auditory abnormalities that have been recorded to date. So there are some puzzles about the whole albino story and the decussation of pathways. It is not entirely clear at the moment where that story may end up, but I would think that most people studying it are convinced that the "chiasm" story is real and that it is part and parcel of the whole question of nystagmus.

Question: This morning you talked about children with cortical insults who do not recognize familiar faces. Is there, in fact, evidence that clinically those kids, because of the cortical insults do not get the same visual information from looking at their mother' faces?

Dr. Hoyt: It has been well described in adult stroke patients, with damage to part of their visual cortex, who have the following difficulties: They have a cortical visual field deficit, cannot name colours, although they can match colours, and they cannot recognize familiar faces. It is a very well described, isolated syndrome that was written up some years ago. It suggests, as many of the basic signs people have, that not only in this visual cortex is there organizations of vision, but in it is organization of small, little functions of vision. There is even an area of the brain that is important for stereo vision, 3-D. Each of those little functions has a hierarchy of its own. What I was suggesting, therefore, is that in these children, that part of the visual cortex which is relatively posterior and is involved in naming colours and recognizing familiar faces, seems to be relatively commonly compromised. I quite agree with you, these children are oftentimes judged to be more

handicapped than they are, because they do not show all the expected responses to their mothers' faces and so forth.

Question: Aren't adult stroke patients different because they have already learned these skills and have now lost them, but an infant never had them?

Dr. Hoyt: Well, now remember, a child will respond to a human face right at birth. Ten years ago in Cleveland Metropolitan Hospital, it was shown that newborns preferentially will respond to a graphic human face before anything else. So if normal maternal bonding is visual, you cannot imagine that the ability to recognize the mother's face is very long in acquisition. I shouldn't say that with all the paediatricians here, maybe they will kill me, but I cannot imagine it.

Question: I wondered if anybody has looked at hydrocephalic children in particular and has seen that they eventually learn to use their vision and as yet they still get impaired information looking at familiar faces?

Dr. Hoyt: Well, the kids that I described today in our study will be published.

Question: Is visual function separate from visual memory? If children match two colours that would be kind of a visual function, and yet visual memory would say, "Well this is red and that is red".

Dr. Hoyt: When we say a child can read, that is not just a test of the sensory system. It is also a test of right/left, up and down, memory and recall, dredging up a word out of the brain to match it, and so on. Therefore, when you talk about these tests, there are obviously different things involved, such as naming, language, etc. Isolated defects of each one of those steps can occur.

Question: Could you discuss optic nerve hypoplasia?

Dr. Hoyt: Well, optic nerve hypoplasia is an interesting story, and it turns out that both the Vancouver people here and myself have been interested in it in almost the same way, so we have two studies that are comparable. There are some interesting historical aspects. If you remember in 1970 there were 17 cases in the world's literature. The Vancouver group published 51 cases recently, and we published almost 100 cases collected

over eight years. There isn't any question that optic nerve hypoplasia represents, in the developed world, a major cause of visual handicap. Now the question is, is the incidence of optic nerve hypoplasia actually increasing, or have ophthalmologists finally tuned in to make the right diagnosis, which is not that easy when there is nystagmus. I think there is a little truth in both of those statements. Whatever the answer is, we see it with increasing frequency. They have well known associated brain anomalies, and our study is quite similar to the Vancouver study. We broke it up a little differently. We said "We will look at kids with severe optic nerve hypoplasia, (ONH) and with bilateral versus unilateral cases and those who have good vision." 60% or something like that, either had abnormal neurologic findings, or a positive CT scan. I used to teach once that the septum pellucidum, which can be abnormal in many of these kids, was nothing more than a strut holding up the ventricles, but then I saw a paper recently, which suggested that it is very important in spatial organizations. We have a number of kids with ONH who sure seem to have trouble with spatial organization and have many other developmental problems. I had always assumed that the corpus callosum is associated with more severe defects than the septum pellucidum, but the long and the short of it is that children with ONH have associated neurological problems in a significant percentage. I think in this day and age not to have a kid with optic nerve hypoplasia seen by a paediatric neurologist or to undergo prospective CT scanning is not up to the standard of medical care in any community.

Question: Is there any relationship in these children between ONH and behavior?

Dr. Jan: I do not think that there is any particular relationship with behavior. Behavior is much more closely determined by the extent of associated brain damage, rather than the degree of ONH. But I do have an interesting comment. The mothers of 50% of the children in our study were quite young, often teenagers. They were drinking during their pregnancies, they were on drugs and had a rather undesirable lifestyle. After my colleague, Dr. Geoff Robinson, learned this, he looked at the lifestyles of other mothers who had children with cerebral palsy, meningomyelocele and other handicaps. But the undesirable lifestyle and young maternal age was only observed in the group with ONH. Dr. Robinson plans to continue this study, because it may explain the upsurge of optic nerve hypoplasia.

Dr. Hoyt: I am sure some doctors have already told you, that in general ONH does not run in families, so that if you have one child with it, the risk of a subsequent child having it is extremely small. There are about 14 cases in the literature with familiar ONH. I used to tell this to all the parents. Then I saw a counter culture family who brought me their first baby with ONH. I said, "You don't have to worry" and she came back about 18 months later, with a second child, who also had ONH. I said, "This is peculiar" and I asked her if she was diabetic, because we know that some diabetic mothers have infants with ONH. Then another 18 months rolled on by and she brought another boyfriend, and a third baby with ONH. Well, I am a slow learner, but not that slow, so I finally asked her about drugs. It turned out she was a fairly florid LSD abuser, and drank alcohol during pregnancies. The Scandinavians, in their long term prospective studies, have just really begun to report the frequency with which ONH occurs in the so-called Foetal Alcohol Syndrome.

Question: Do you have pictures of ONH?

Dr. McCormick: I have several pictures of optic nerve defects -- a little boy who suffered an injury to his optic nerve, and in fact it is dead. That means that millions of fibres from the retina, which go through the optic nerve to the brain, were cut off. This is an interesting picture for a couple of reasons. The blood vessels on the retina are supposed to be within the retinal substance. However, when the retina is greatly thinned, due to degeneration of all the fibres that are going to make up the optic nerve, the retinal blood vessels will appear to float on the surface of the retina. You can get that feeling from the picture.

--- In another picture ---the optic nerve is enormously enlarged. I do not know why, but it is just the kind of optic nerve built by a committee. The vision is very bad. There are a lot of variations in optic nerves and many just do not work very well.

--- In a third picture --- the optic nerve is very minute. It is less than 1/10th of the normal size, so it could not have any more than a tenth of the fibres. Furthermore, many of the fibres do not work properly.

Question: Do optic nerve heads change as the child grows?

Dr. McCormick: Yes, the optic nerve gets bigger with time, but hypoplastic optic nerves will always be small.

Question: How much vision does a child with ONH have: Does it vary?

Dr. McCormick: It varies from having perfectly normal vision to being almost blind.

Question: What were the causes?

Dr. McCormick: We are not just sure about the causes. In our own experience here, youthful maternal age is related to the disorder and also drugs and alcohol intake. But that is not to say it is a matter of cause and effect.

Question: Can the father be responsible by taking alcohol?

Dr. McCormick: I think it is the mother.

Question: I have a daughter with coloboma and nothing has been said so far about this eye disorder. Why did it happen?

Dr. Hoyt: In the situation of a coloboma, we are certain that the insult is in the first trimester, usually between 4 to 8 weeks of gestation. That is when the foetal fissure closes. We know what causes the coloboma. Coloboma comes from the Greek word meaning "multilated" and it means that it just did not come closed. Children with coloboma generally do not have endocrine problems, but children with ONH do. At UCSF, I have gone around for four years saying "Kids with optic nerve hypoplasia have to have a complete endocrine work-up". And every time we send them in and they have mild thyroid disease, or something else. Our neurologists are very concerned about that. Thyroid hormones are important in normal nerve growth. Therefore hormonal abnormalities are not a minor issue.

Question: Are there other hormones which may also be missing?

Dr. Hoyt: In our experience thyroid deficiency is the most common, but growth hormone deficiency, panhypopituitarism, diabetes insipidus are also frequently diagnosed. The study at Los Angeles Children's that Dr. Murphree and his endocrinologists are just about to put in the paediatric literature, shows that there are something like 40% of ONH children with endocrine abnormalities when they were worked up.

Dr. Jan: Not only that there is too little hormone production, but sometimes there is too much.

Question: I have a general question. I see a number of premature children who are profoundly brain damaged, and now have cortical blindness. Their eyes are normal. Now the teachers and therapists who work with these children, of course, wish they could see, and they sometimes are convinced that they can see. Can the ophthalmologist tell whether the children can see?

Dr. Hoyt: Lots of times they cannot. We talked about this diagnostic dilemma this morning. Let me just have you do a quick experiment. Put your finger in front of your eye and move it slowly while you are looking at it, but hold your head still. Watch what happens as you move your finger slowly. You have to move slowly, very slowly. What happens to the room behind your finger? It rotates in the opposite direction. We produced the so-called tracking eye movements. They are of no use to anybody, except when you go to a doctor, who says "follow my finger". If you use those to read, as you go across the page to the right, the desk would move to the left. That is not what happens. So, when we judge someone's vision by the way they fix and follow, we are testing another system. Therefore, when you take a toy and move it quickly in front of a child, you are really not testing his vision.

And now, let us do a new experiment. Just pick out a couple of people on either side of the room in front of you and look quickly from side to side. Tell me what happens. Do not move your head, just move your eyes quickly. What happens to the environment now? Nothing happens. You ought to have the same effect that the room is moving. Well, when you move your eyes so quickly the brain turns the vision off during that time. You move your eyes in a 600 degree arc per second and that is like trying to take your arm and take it twice around your shoulder in a second. The fastest muscle movement in the body. The vision is turned down to about 20/200 when you do it. And you only move about 5 to 6 degrees and the brain fills in. That's the only system that shows whether a child can see anything, because you can say that the child saw this target. Fast eye movements are generated from the frontal cortex. So, if you take blind children with cerebral palsy, and spin them, you will find that they do not always get nystagmus. You spin a child with cerebral palsy, nine times out of ten they let their eyes drift off to the corner and they do not come back

fast to re-fixate, because they cannot generate those fast eye movements. So we have to be careful when we say, because they do not fix and follow an object, that they are blind. Now, you ask, how can I say that the child does have vision? The visual evoked potential studies are not that great for testing visual acuity. We have talked about the problems of CT scanning. So it is very difficult.

Question: Is there any research going on into devices which bypass the eyes or optic nerves of blind children?

Dr. Hoyt: Yes, there are at least three approaches. The most basic approach has been primarily done in Scotland, using what is called "substitution sensory mechanisms". They set up children essentially with a radar device, that has three qualities, pitch, a tone and volume. These change as the child moves closer or further away from an object. The preliminary work that has been done on these devices is very impressive. It is a crude device, however. It does not have the potential to be anything more than a kind of volume detector. It detects something that is getting closer, or further, which is relatively dense or soft. So, it has the potential for mobility but not much else.

Some researchers have bypassed the eyes in blind experimental animals by feeding electrical currents from photoelectric devices directly into the visual cortex. The results have been depressing, because the monkeys can respond only to large objects and keep from bumping into things. Trying to bypass the eye and go right to the brain is not only an electrical but a developmental problem. When there is lack of normal vision early on, the visual brain does not develop. Some experiments have been done, primarily in West Germany, trying to look at ways to promote growth of cells into non-damaged areas. So that those are the three places that I think research is going on. Each has some potential. I think they are a long way away from being commonly used.

CONCEPTUALIZING THE GIFTED BLIND CHILD

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Educational programs for developmentally delayed blind children have received significant emphasis over the past few years. Important progress has been made in establishing and facilitating the most appropriate ways to meet the individual needs of visually handicapped children who have other handicapping problems.

There is more to be done for children with developmental delay, and there continues to be a need for better services for this multihandicapped group of children. My interest certainly remains keen in the areas of educational services for multihandicapped blind children.

However, as educators of visually handicapped children, we must examine the needs of all of these students who are entering our educational system. Among the population of blind students we see a somewhat neglected group which could be identified as those students who are potentially gifted and talented. It is to this group of learners that I wish to direct our attention and I will confine my remarks to the Braille using congenitally blind child who is about to enter the school system at five or six years of age.

My search for literature on this subject has only served to reveal that these youngsters have been given very little, if any consideration in studies made regarding the education of the blind. Because of the lack of research material to substantiate my study, I have had to rely on the personal experience I have had during the past twenty five years in designing and implementing programs for young bright blind children and examining similar programs with my colleagues.

We have found over the years at the W. Ross Macdonald School, that in our general school enrollment of blind students, according to intelligence, our students are not distributed on a normal bell shaped curve with most children clustering around the average.

We find more students than we would expect statistically at the upper or intellectually gifted end, and more students at the lower end. Our middle range has fewer students than one would expect.

Since many blind children are multihandicapped and evidence some brain damage, it seems logical that we would indeed be dealing with a larger number of children who experience learning difficulties. However, we are at a loss to explain why we also see a larger number of intellectually bright students. We have found, as others have found, that students blinded from retinoblastoma generally show above average intelligence. Although the retinoblastoma children often fall into the gifted grouping, they do not hold exclusive rights to high ability. Most of our bright students have different causes for their blindness.

Jefferson once stated that there is nothing more unequal than the equal treatment of unequal people. Blindness makes a child unequal. Giftedness makes a child unequal. When both exceptionalities appear, that child needs special and different educational opportunities that go beyond equal education for all children.

The Ontario Ministry of Education has defined giftedness as: "An unusually advanced degree of general intellectual ability that requires differentiated learning experiences of a depth and breadth beyond those normally provided in the regular school program to satisfy the level of educational potential indicated." [[Special Education Information Handbook 1981. (Toronto: Ministry of Education and Ministry of Colleges and Universities, Ontario, 1981) p.44]].

There are two main concerns that face educators of young blind children who appear to be bright and talented.

A. How do we identify the Gifted Blind Child?

B. How do we provide for the scope and sequence of the curriculum so that the special needs of both exceptionalities will be satisfied?

<u>Identification:</u>

There are many characteristics set forth by qualified professionals that can be used to identify giftedness in the visual child. Can these same characteristics be used to identify giftedness in the blind child? Before we can answer that question, we should briefly review the uniqueness of development in a child who has never seen.

Lack of vision affects all domains of development - psychomotor, cognitive and affective. Without vision to conceptualize total pictures of themselves and the environment, blind children are limited in ability to acquire the range and variety of experiences that sight automatically puts together for the visual child. No matter what intellectual capacity the blind child may have, learning is begun differently because information comes from stimuli which are processed through the remaining senses without vision to unite the whole scene. Vision makes concepts meaningful and clearly understood at a glance.

The literature may define a blind child as a child - and that is a good starting point. But, as a total person, and if that person is to grow up well adjusted, blindness is just as much a part of that child as red hair, freckles and fair skin. A blind person once told me that it was as normal for her to be blind as it was for me to be sighted. Blindness must be accepted as a characteristic of the child that cannot be dealt with separately but must be included when we are identifying the needs of the whole child.

Gifted blind children are unique in their development. Characteristics of blindness may either mask or distort the characteristics commonly ascribed to giftedness. Let us look at a few of these characteristics that are used to identify giftedness in visual children and then see how blindness may render these same descriptors inappropriate for the child who has never seen.

<u>I.Q. measurement:</u>

I.Q. measurement is a prime instrument in identifying bright students. In the primary years of schooling, this is a totally unreliable method of finding giftedness in blind children. The consequences of never having sight puts the school age blind child's development at a disadvantage and I.Q. testing will not readily indicate intellectual potential. In fact it may give false information that will discourage teachers from challenging the child's true ability.

If we do not believe in fixed intelligence in visual children, we can be assured there is no such thing in blind children. Changes - and usually dramatic changes - occur with stimulation and experiences. Intelligence should only be one of the considerations in identification. Many aspects of the blind child's giftedness cannot be measured by I.Q. tests because thinking powers of the blind child may lag at first. Development must be viewed as the total integration of all of the child's functions - the interaction of thinking, feeling, responding, etc.

If the child can bring high intelligence to this total picture, that child will be able to think more holistically even though vision is absent, and therefore become more of a self-actualizing person. Gestalt's theory applies here - the whole is more than the sum of its parts - one system depends on all other systems. The blind child must be viewed as a total child who needs to develop cognitively but at the same time show growth in all the areas necessary to function as a capable and confident human being.

Intelligence encompasses the ability to generalize, to form concepts, to reason abstractly and to solve problems. Some of this capacity may be inherent, but much of it is acquired. Again the blind child is disadvantaged in these capacities because of early fragmented concept development. With intervention and programming the child will be able to show substantial gains in these various areas. This takes time and effort but results will be evident and generalization abilities will improve. For example it takes time for the blind child to experience and to understand that a Great Dane has certain canine characteristics that can also be applied to a Poodle. This kind of generalization is difficult for blind children and takes more time and experience to acquire.

The caution is to avoid using standardized tests for the purpose of early identification of the gifted blind child. The child should have at least two to three years of solid and specific programming before intelligence tests that will become part of educational records are administered. Formal intelligence testing eventually can become part of the total identification process for a child suspected of being gifted. The results can yield valuable information if interpreted by a professional experienced in assessing all types of blind children. This sort of evaluation can serve to establish a baseline and can give indicators of potential and thus help to establish the need for a planned programme of guidance and enrichment of all experiences: academic, social, athletic, aesthetic and life coping skills.

<u>Language:</u>

Can we use language as an indicator of giftedness? A high level of verbal ability can determine good intelligence. However, once again, lack of sight can interfere with comprehension. Therefore verbal ability should not be taken at face value but it should be verified with an examination of the child's thought processing, comprehensive synthesis, information gathering, integration of information, generalizing, and use of original ideas.

Many blind children at four or five years of age may have poor language development - but may acquire language facility later as they integrate concepts and understand information. When they begin to use language meaningfully and fluently, they can blossom and often show exceptional abilities. Language may be an indicator of giftedness in blind children but it should not be taken as the only sign nor should giftedness be discounted if high verbal ability is not present at four or five years of age. Language should be examined to be sure it is being used meaningfully and in functional context.

Creative and productive thinking:

This characteristic is used to identify giftedness and blind children may certainly show these abilities. We are quite sure though, that children cannot create well in a vacuum. Blind children may start school with a sparsity of experiences and incomplete generic ideas. They may not have a good background from which to develop imaginative thinking. We must also make sure that these children spend most of their time in reality since it is easy for them to build fantasies when sight does not interfere with day dreams. Reality based participation can nurture creativity. Early identification of giftedness should not be dependent on the ability of the blind child to think creatively at first. It may be difficult for some able blind children to develop creative play in their early years, using concrete materials like dolls, dress up clothes, play house and furniture. Early help to play constructively will assist later creative play techniques.

High capacity for seeing diverse relationships:

The very nature of this ability is hampered by the limitations blindness imposes in constructing holistic concepts in an integrated way. Interpretations can be very pure to blind children who have difficulty realizing the shades and diversities of meanings that accompany any one item, activity or spacial relationship. When sight is lost, using the four remaining senses to discover the world constricts the blind child's capacity to understand a variety of diverse relationships on both the concrete and abstract levels.

Goal oriented behavior:

This trait of the gifted will eventually evidence itself in bright blind children. However, the possibility of choices may not be as easily understood. These youngsters tend to choose from what is known to them and not reach out to discover the world beyond arm's length. This less efficient method of contacting the world can lower the child's motivation towards self initiated goals and towards

exploration and manipulation of the environment. It can also result in a passive attitude to learning where the child both physically and intellectually waits for the teacher to bring the world to him and also interpret it to him. This passivity invades the mental process and decays the child's natural tendencies to explore and "play" with thought.

Sensitivity to expectations and feelings of others:

Body language, gestures, etc. in others gives us excellent information regarding the effect our behavior is having on people around us. This information is acquired mainly by vision. Blind people do not have this advantage and often must wait until they receive impressions from verbal interchange or from the created atmosphere to learn how their friends and associates are responding to them. They do not have sight to verify their interpretations and they cannot immediately perceive the results of their actions, so purposeful behavior may lag.

Social competencies - self awareness:

Gifted visual children are known to have a high level of self awareness. This self concept may include feelings of being different. Blind children may not perceive themselves as different in their early years and they will learn self concept differently because they cannot make visual comparisons with peers. Their idea of themselves will reflect the input and attitudes of significant others in their lives. They may take longer to learn acceptance of self and gain confidence to project a positive self image. A blind child who presents as a behavior problem may have the behavior accepted or excused because of blindness. Blind children need to know appropriate behavior and what is expected in various situations. Inappropriate behavior can shadow the talents that may be inherent in the child.

A gifted child may place high expectations on self performance. If these expectations are not met, frustration levels may rise. Many blind children have difficulty accepting the idea of making mistakes as an important part of learning.

When the blind child begins to know the world around him well enough, he can begin to exert a purposeful influence on what is happening around him. Bright children will show good interest and curiosity about how things are happening and the ways in which they can make them happen. Enhanced self awareness and social skills will assist the bright child to reach out for more information.

Bright blind students are in the same uncomfortable position that bright young people of other minorities are in - blacks, natives, divergent cultural or socio-economic groups. Should they blend or integrate into the general population or should they assume a position of leadership within their own minority? Whichever road they choose to take they will be very noticeable and will therefore experience more stress than many of their peers. We have a responsibility to help them develop strong, well adjusted personalities both to help them manage the stress and also to help them project the most positive image of themselves to others.

Motor performance:

In identifying giftedness and talents, we should be careful to include an assessment of motor performance. In this area too, blind children could show a discrepancy between physical and intellectual development. For example, children whose blindness was caused by retrolental fibroplasia and who began life with a low birth weight could physically present as a three or four year old when they are six. One may see an advanced six yer old cognitively who functions motorically well below the six year old level. The reverse development could also appear.

Educators are aware that many blind children, because of other physical problems or lack of visual goals to move towards or long confinements in play pens, may not have developed free and natural movement. Movement is absolutely essential in order to contact the environment and to explore and experience objects and space. Movement is synonymous with learning. therefore if movement and spatial awareness have been impeded, learning may be delayed - but intellectual capacity to learn may still be excellent.

I have tried to describe the problems we have in identifying giftedness in blind children if we use the traditional measures and characteristics applied to gifted visual learners.

If we accept that blindness causes intricate complications in all domains of the child's development, then we will understand how this uniqueness can be misinterpreted and even mask the talents and gifts that may be waiting to be developed in the blind child.

From our experience, comparing the functioning of a sighted child with that of a blind child of similar age is a useless and unfair estimate of operational abilities and potentials.

If we cannot use I.Q. scores and other inventories for identification of the gifted blind child, what then can be used?

I personally believe the best tool for identifying the Primary School and even the Pre-School gifted blind child is OBSERVATION by experienced and knowledgeable observers who have seen many blind children. Parents should be the first source of information. Teachers should be trained to understand how blindness affects early development. They should be trained to provide a good introduction to basic academic subjects. They should watch and keep anecdotal records as the child moves along and interacts with all phases of the program and all types of stimulation. Combined observations should be made of the whole child relating to and responding affectively, cognitively and motorically to experiences and environment. These observations will reveal emerging talents that can be nourished as part of the total developmental process. Watching the results of intervention and specific skill introduction will give good clues regarding the child's emerging abilities.

Once we suspect exceptional abilities and begin to see them flourish - and become solid, we will then be able to administer some of the tests to verify our predictions.

Programming Advice to Uncover Giftedness and Help it Grow:

At the outset, I would like to take the liberty of offering some advice to teachers who may be meeting their gifted blind youngster in kindergarten or grades one, two or three.

1. Because these children appear competent and verbal they may be treated as very "special". In young blind children, we should avoid making much of their "specialness". Socially, they should be treated as much as possible the same as their peers. Give them similar privileges and similar responsibilities. The influence of adults who talk up the child's brilliance ahead of other personal characteristics should be avoided. Blind children should feel special because of themselves as people not because of isolated qualities like blindness or their superior intelligence. Praise should be given only for accomplishments not attributes!

2. Because they appear very competent and verbal and because they seem to learn easily, we may accept that they are doing as well as they can, and fail to stretch and challenge them through enrichment and appropriate placement.

3. Because they show particular talent in various areas, all emphasis may be put on extending that talent to the exclusion of other experiences that are vital to give the child a well rounded personality and self concept. In other words, too much practice to "become better" at what they do well may cause them to miss their childhood and weaken other areas of potentially high function. This treatment will no doubt produce a perhaps bright but narrow minded and poorly adjusted adult.

4. Don't move too quickly to load the child with "extras". Design an individualized, structured, sequential program and build in a strong foundation of core subject areas - reading - writing - mathematics - concepts - orientation and mobility and living skills. Teach heavily in these areas in the Primary years. Provide opportunities for creative expression in the Integrated Studies segment of the Curriculum.

5. Consider placement either in Residential or Integrated settings in academic grades for the first three years. In the case of integrated settings, withdraw only for times of specific skill instruction i.e. Braille - abacus, etc. By grade four (keep flexible depending on the child) we should begin to look at Programs for the Gifted and identify the exceptionalities as Blind and Gifted for purposes of programming. Branching out to computers and other technical devices will become appropriate.

<u>Needs of the program - essentials of the curriculum:</u>

Gifted and talented blind students need a different philosophical approach to their education, yet they need the same solid educational base set for any child who has never seen. It is from this dichotomy that I wish to mention certain basic needs that I feel should be part of every blind child's early education. These needs are critical to the development of the whole child.

The bright blind child, because that child may appear exceptional in verbal or musical abilities, could cause the teacher to feel that concept development, social relationships, etc., are lesser needs.

Educators are becoming concerned with basic principles of neuropsychology. They are becoming interested in how information is processed. What happens between input and output of information? The study of behavior and the knowledge that all systems must be in harmony would encourage us to teach to both hemispheres of the brain.

For blind children, this is a vital consideration. The needs I am about to list may seem self evident. Yet I feel they are being missed in some programs where the blind child's cognitive level may seem to the teacher to be too high to dwell on these basic necessities.

A. Need For Cognitive Development:

1. Concepts of self and environment
Experienced based curricula will foster the cognitive development of blind learners. Piaget's theory and stages of development can apply directly to blind children. Intelligence, according to Piaget, emerges as it is nurtured and grows as the child has things to act upon and with which he can interact.

For the blind child, continually reinforce the idea of ME as a whole person - what I look like - What sex I am - how tall I am - what is unique and wonderful about ME? How does my blindness work for me as part of my total being? Continue to find out how to relate to the environment - special relationships - others and items around us and their functions - times - hours - days - weeks - months - years - seasons - specific times of routines and activities - special days - concepts of atmosphere - weather temperature - ideas of comparison - size - texture - function - position - shape - form - generalization - categorization - order and ideas of reproduction.

Experience, experience, experience with the whole body using and integrating all remaining senses to put holistic scenes in place. The teacher is the coordinator putting varieties of information in balance with each other - explaining - exploring - reinforcing and building confidence. Always be aware that the problem with being blind is the fragmented exploration that is necessary in examination. Language worked meaningfully around experiences can greatly ameliorate this problem. Encourage the child to explain in terms of his own sensory information.

2. Academic competencies
Reading and writing by means of Braille is another road to freedom. Braille I believe, should be the priority medium at first and never be replaced by more modern reading machines like Kurzweil and Optacon - although these should be used as supplements later on. Introduce the slate - and work for high proficiency; this is the blind student's pen and pencil.

Far too many bright blind children are imcompetent readers and writers because they are allowed to move to other devices before they have mastered the Code. Some children may even need remedial lessons in Braille. The key to early fluency in Braille is a great deal of exposure to the Code - just read, read, read and enjoy. Do not spend a disproportionate amount of time in questioning for comprehension. The focus should be on being able to recognize the Code, and read it fluently. Comprehension will come later. If the child is unable to decipher the Code - he will not like to read and his desire and motivation for reading will be stifled. We, in our school, have substantial proof that children taught to read the Code by a great deal of exposure in the first years, with heavy emphasis on phonics, progress more quickly in reading skills than children who have had more emphasis on comprehension than on cracking the Code.

What I wish to emphasize is that the basics for bright blind children must not be overlooked - reading, writing, mathematics, listening, speaking, concept development, orientation and mobility and living skills should be structured and sequentially programmed. Integrated Studies in art, music, drama, physical education, social sciences, current events, etc., are the areas in the school day for more creative expression.

B. Need for Psychomotor Development:

Movement and preceptual-motor activities are requisites for learning. Gross Motor movement of every description is important to the blind child in the Formative Years. Build movement education into as many areas of the child's curriculum as possible.

Teachers should know basic mobility and pre-cane techniques. Effort should be made to encourage free and natural movement. Only after these skills and this freedom has been established should the cane or other devices be offered.

Independence in all areas of the child's life is the greatest gift we can offer the blind child.

Fine Motor tasks, the constructive use of both hands, the facility of mid-line hand positioning and directionality are all much needed skills to accomplish.

In early education, moving competently is more important than reading or playing the piano. Mannerisms will be reduced if movement programs are stimulating and introduced in infancy.

A physiotherapist who knows about blindness is a helpful member of the education team. Only through moving, can blind children know the world outside themselves.

Need For Affective Development

Of the areas of development, perhaps this is one of the most important. Blind children have a special need to fulfill Maslow's hierarchy and prepotency of needs - Physiological, Safety, Love and Belonging, Esteem, Self Actualization and the Need to Know and Understand. A positive self image is so essential. The child with good ability must know that he can accomplish because of his ability - not in spite of his blindness. Earned and honest praise, equal responsibilities, healthy competition with sighted peers and if possible with other blind children is helpful.

Gifted children can have unusually high expectations of themselves. This pressure can be more demanding than external pressure. They may need help in acquiring realistic goals and more adequate coping behaviors. Gifted blind children can become accustomed to hearing that they are "best". They may begin to consider everything they do to be exemplary. They must be allowed to make mistakes and to know that others make mistakes too and that this is part of learning.

Some blind children on the other hand, may have difficulty verbalizing what they feel they can do well and will need help to recognize their abilities.

The blind child's awareness and understanding of who he is as a whole person will have a great influence on his developing quality of life.

Above all, gifted blind children need to have their childhood. They must experience love and enjoy life to the fullest. If practising music and studying electronics is taking up most of their free time, they will not develop socially or emotionally. We all know the eccentric genius who can make a great contribution to the class, but I have also known that genius to experience extreme depression and loneliness. By looking at our adult gifted blind people, the most productive and satisfied individuals are those who have had a loving, secure, fun filled and happy childhood with a great variety of experiences.

Placement and Program Delivery

Is it acceleration or enrichment that will best suit the needs of gifted blind children? In the first years, I strongly

advocate specific skill development designed, monitored and directed by a Specialist Teacher of the Blind. As mentioned before, areas like drama, music, crafts, etc. can be vehicles for creative expression. The individual must be treated according to progress and program but generally speaking, enrichment is by far the best option. The decision for placement will be dependent on what is available in the community. Eventually, the child, (perhaps at about grade four) should be put into an enrichment class with other bright children who are in the hands of a trained Teacher of the Gifted and that teacher should then work cooperatively with the Specialist Teacher of the Blind. These teachers together with parents can encourage creative productivity and make giftedness "happen" in the student who shows this kind of potential. Enrichment may focus heavily on the child's strength area - but while this is appropriate, development of the whole child is of paramount importance. Reaching out to all community resources is essential.

Our students must have the opportunities to develop competencies in order to free creative and productive powers. Thoreau once said, "Birds never sing in caves". They also cannot fly without wings. Providing young blind children with the kind of early intervention and skills they need will give them the wings to be creative and will release them from mimicking visual ideas of others and give them the confidence to be themselves.

CONCLUSION

Blind children need love and acceptance in their early years. They need the kind of love that is a process of giving them belief in themselves. They need informed and loving teachers who can help them understand themselves and their environment so that their special talents may be uncovered and enhanced. Assessing their potential strengths by traditional measurements is unfair in the early years because of the different ways they process information.

Gifted blind people should be leaders and contributors in society. Educators have to assume their part in the responsibility of helping them become everything they can be - not only for themselves but for all of us.

REFERENCES & BIBLIOGRAPHY

Anderson, K. (Ed). Research on the Academically Talented Student. Washington, D.C.: National Education Association, 1960.

Ausubel, D.P.: Cognitive Structure: Learning to Read. Education, 1967, 87, 544-548.

Barron, F.: Creative Person and Creative Process. New York: Holt, Rinehart and Winston, 1969.

Binet, A., & Simon, T.: The Development of Intelligence in Children (the Binet-Simon Scale) (E. Kite, trans). New York: Arno Press, 1973. (Originally published, 1916).

Brant County Board of Education: Program Proposal for Education for Gifted and Talented Students, 1981.

Briggs, D.: Your Child's Self-esteem: The Key To His Life. Garden City, N.Y. Doubleday, 1970.

Bruner, J: The course of cognitive Growth. American Psychologist, 1964, 19, 1 - 15.

Callaway, W.R.: A Holistic Conception of Creativity and its Relationship to Intelligence. The Gifted Child Quarterly, 1969, 13, 237 - 241.

Clark, Barbara,: Growing up Gifted. Columbus: Merrill, 1979.

Cratty, Bryant J.: Movement and Spacial Awareness in Blind Children and Youth. Charles C. Thomas, 1971.

Elkind, David,: The Hurried Child - A Growing up too Fast too Soon. Addison-Wesley, 1981.

Farrell, P.: Teacher involvement in Identification. Paper presented at the First National Conference on the Disadvantaged Gifted, Ventura, C., March 1973.

Feldenkrais, M.: Awareness through Movement. New York: Harper and Row, 1972.

Fraiberg, S.: Parallel and divergent patterns in blind and sighted infants. The Psychoanalytic Study of the Child, 1968, 23, 264 - 300.

Fraiberg, S.: Insight From the Blind. New York: Basic Books, 1977.

Gallagher, J., & Kinney, L., (Eds.): Talent Delayed-Talent Denied, the Culturally Different Gifted Child. A Conference report. Reston, Va.: The Foundation for Exceptional Children, 1974.

Holt, John,: How Children Learn. New York, N.Y. Dell Publishing Co. Inc., 1967.

Hopkins, K.D., & McGuire, L.: Mental measurements of the Blind. The validity of the Wechsler Intelligence Scale for Children. The International Journal for the Education of the Blind, 1966, 15, 65 - 73.

Kaufmann, F.: Your gifted child and you. Reston, Va.: The Council for Exceptional Children, 1976.

Kohlberg, L.: First Things: Social development - grades 2 to 5. New York: Guidance Associates, 1974.

Krech, D,: Don't use the kitchen sink approach to enrichment. Today's Education. 1970. 59, 30 - 32.

Maker, J.: Providing programs for the gifted handicapped. Reston, Va. The Council for Exceptional Children, 1977.

Mallinson, T.: Gifted Underachievers. Toronto: Ontario Board of Education, Research Department, 1972.

Ornstein, R.: Right and left thinking. Psychology Today, 1973a, 6, 87 - 92.

Piaget, J. & Inhelder, B.: The Psychology of the Child. New York: Basic Books, Inc., 1969.

Pledgie, T.K.: Giftedness among handicapped children: Identification and programming development. Journal of Special Education. 1982, 16 (2), 221 - 227.

Rogers, C.: On Becoming a Person. Boston: Houghton Mifflin, 1961.

Samples, B.: Learning with the whole brain. Human Behavior, 1975, 4, 18 - 23.

Special Education Information Handbook 1981. (Toronto: Ministry of Education and Ministry of Colleges and Universities, Ontario, 1981.

Strang, R.: Helping your Gifted Child. New York: E.P. Dutton, 1960.

Swallow, Rose-Marie: Piaget's Theory and the visually handicapped learner. The New Outlook, September 1976, 273 - 280.

Thinking Caps: Materials for gifted: Cognitive, affective, psychomotor skills and activities, Box 7239, Phoenix, Az. 85011.

Tillman, M.H.: The performance of blind and sighted children on the WISC: Study 1. The International Journal for the Education of the Blind. 1967a, 16, 65 - 74.

Tillman, M.H.: The performance of blind and sighted children on the WISC: Study 11. The International Journal for the education of the Blind. 1967b, 16, 106 - 112.

Web, D.: Teacher sensitivity: Affective impact on students. The Journal of Teacher Education. 1971, 22, 455 - 459

Williams, M.: Superior intelligence of children blinded from retinoblastoma. Archives of Diseases of Childhood. 1968, 43 (228) 105 - 115.

Warren, D.H.: Blindness and Early Development. New York: American Foundation for the Blind, 1977.

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THE EFFECT OF MOTOR HANDICAP ON THE DEVELOPMENT OF VISUALLY IMPAIRED CHILDREN

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When a child is born with multiple handicaps, parents and teachers often have difficulty analyzing his developmental problems, and interpreting his behavior. Several authors have described the compounding effect of multiple handicaps with blindness in retarding various areas of development (Jan et al, 1977, Warren, 1977). There have been a number of publications aimed at providing direction for parents and others working with children who are deaf as well as blind (Freeman, 1970, McInnes et al, 1982). However, little published material is available for those who must care for the motor-handicapped, visually-impaired child. It is the purpose of this paper to analyze the interactive effect of these handicaps in an effort to better understand the child's difficulties, and to present some recommendations for intervention which have been found useful for children we have seen in the Visually Impaired Programme at Children's Hospital.

Cerebral Palsy

Surveys of visually impaired children have shown that the incidence of cerebral palsy is between 10% (Robinson, 1974) and 23% (Scranton et al, 1978). Since this is such a common diagnosis, it is important that all concerned be very clear on the definition of cerebral palsy. For the last twenty years, the definition accepted by the American Academy for Cerebral Palsy is as follows: "...a disorder of movement and posture due to a defect or lesion of the immature brain." (Bax, 1964).

It is thus seen that the term is inexact, covering a broad range of handicaps from minor to severe. Frequently, even when parents are already aware that there has been damage to their child's brain causing a motor problem, they can become extremely alarmed when the diagnosis of cerebral palsy is first made. It is of utmost importance that clinicians define what they mean by the term in order to reduce the stigmatizing effect, and reassure parents as to the implications.

When assessing children with cerebral palsy, one usually discusses the prevailing muscle tone. This can be high (hypertonic or spastic) or low (hypotonic). There is frequently a combination of low tone in the trunk and high tone in the limbs. The distribution of the abnormal tone is also important: it may be restricted to one side of the body (hemiplegia), to the legs (diplegia) or affect all four extremities (quadriplegic). Rather than carrying out a comprehensive discussion of cerebral palsy, we will examine some aspects which have special significance in the presence of visual impairment.

a) Poor head control

A child with minimal partial vision and poor head control is unable to reliably position his head so as to try to use the remaining vision. Although he may be able to momentarily hold up his head, by the time he manages to focus on the object of interest, his head may have moved, and he will no longer be able to see it. Even if he is able to hold his head up for several minutes at a time, it is probable that when a great deal of energy is channelled into maintaining head control, there is little energy left for looking and learning.

In a study of fifty children with cortical blindness seen at Children's Hospital Visually Impaired Programme, almost all of the children with good head control went on to develop some useful vision, while all of those with poor head control failed to develop useful vision. In several cases, it appeared that early sporadic visual responses diminished in frequency and finally ceased, as the child received so little reinforcement for his efforts to see.

While the exact cause and effect relationship between head control and vision is not clear, it was considered worthwhile to provide some type of head support to these children with poor control, to be used during periods of visual stimulation. We are presently experimenting with a tubular orthotic collar (Hannah and Cottrill, in press) which is rigid, though light, relatively comfortable, and easy to keep clean. Clinical observations would suggest that the children who have worn the collar have benefitted, and more formal studies are planned. Although the collar has so far only been used with cortically blind children, there is no reason why it should not be used with children suffering from other visual impairments, who lack head control.

Such an approach is not without controversy, for there is bound to be concern that providing support for the head may delay the child's acquisition of independent head control. It is important, however, that all aspects of the child's development be considered. Thus, the child can work on head control as part of his motor programme, and wear a head support when working on increasing visual efficiency, and eye-hand co-ordination.

b) Lack of mid-line orientation of the hands

The posture of a child with severe spastic cerebral palsy is often dominated by reflexes which he cannot control. One of these, the asymmetrical tonic neck reflex, causes the child to adopt a "fencing" posture. Typically, the child lies with his head turned to one side, with the arm and leg on the face side extended, and the arm and leg on the skull side flexed. The tonic labrynthine reflex causes the child, when lying on his back, to arch his neck, pull his arms back with fists clenched, and rigidly extend his legs. Frequently, aspects of both these reflexes may be observed in the same child.

These reflexes have a wide range of serious effects on the child's motor development. For the visually impaired child, one of the most significant effects is that he is prevented from bringing his hands together at the midline for exploration of his body, for grasp and tactile exploration of a toy, or for bringing an object to his mouth or up to his eyes. One simple way to help the child bring his hands together is to turn him onto his side for play, and this is one of the least complicated positioning techniques that can be used with a severly handicapped child. Naturally, an important goal of physiotherapy with such a child is to enable him to keep his head in the midline, with hands forward, in a more upright position. Therapy should begin as early as possible, in order to be most effective, and should be carried out, if at all possible, by a therapist who has received special training in neurodevelopmental techniques.

The child with very low muscle tone also has difficulty attaining a midline orientation, as the head frequently falls to one side, and the limbs tend to be pulled down by gravity into a "frog-legged" position. The side lying position may be useful for this type of child as well. If the child is small enough, a position of back lying on his mother's lap, with his head supported in the depression between her knees and his legs up on her chest is useful. Benefits of this position are that the child's head is maintained at midline, where he can see his mother's face, if she comes close, and vision is sufficient. Also, he can be assisted to bring his hands to explore his head, trunk, legs and feet, and to also

explore his mother's face. The mother can also help to improve the tone in the trunk by repeatedly pushing down on the shoulders, causing co-contraction of the trunk muscles, but these and other treatment techniques are best taught and supervised by the child's physiotherapist.

As we have seen, visually impaired children need to be able to maintain a midline orientation of the head and hands in order to develop efficient use of partial vision and touch. As soon as sufficient postural stability has been attained, it is important that the child be provided with a chair which has a large tray. The tray will provide a convenient surface, close at hand, for exploring toys both tactually and visually and the lip around the tray prevents them from getting away. Although a standard highchair can be used, most parents find that a "floor-chair" or "corner seat" is more useful. Such a chair can be cheaply constructed out of plywood, custom made to provide for the child's particular requirements, and does not present the hazard of falling from a height.

c) Lack of tactile discrimination

When observing a cerebral palsied child with significant spasticity in the upper extremities, we are instantly aware of his difficulty in reaching, grasping and releasing objects - the motor aspects. What we cannot observe is the presence of sensory deficit in the hands as well, ranging in severity from complete numbness to a mild difficulty in discriminating tactile information. Many children with abnormal tone demonstrate "tactile defensiveness", where tactile input produces feelings of discomfort.

The sense of touch is vitally important for manual function in sighted as well as blind persons, as we have all discovered when suffering transient numbness of a hand due to pressure on the ulnar nerve at the elbow. But the blind child who is deficient in his sense of touch to the point where he cannot perceive the distinguishing features of an object through handling it, is truly suffering from a multiple sensory deficit. Fortunately, a number of methods are available which may help to improve tactile discrimination:

1. Midline orientation of the hands, as has been mentioned, is vitally important, and is a primary goal of early therapy.

2. If the hands remain fisted, fingers should not be pried open, but stimulated to open by themselves through stroking of the back of the hand, or downwards pressure on it. The thumb can be released from the palm by gentle squeezing of the fleshy area at its base.

3. Weight-bearing on the palms of the hands is important, as there is some evidence that this stimulus aids in the development of the tactile receptor cells (Dellon, 1981). If the child initially resists the prone position, he can be helped to push on walls, furniture, his parents' hands or chests, and so on, until sufficient shoulder and elbow stability has been achieved.

4. Stimulate the sense of touch with a variety of textures. One can use a variety of materials, soft brushes, and so on. Even when the child is being casually held, without special materials close at hand, he can be helped to experience the difference in feeling between the skin of the parent's hand and her clothing.

5. Go slowly in the presence of tactile defensiveness. At first, the child will only be able to tolerate very brief contact with a stimulus, and he should feel confident that he will not be forced beyond that point. With patience and persistance, the length of time spent in manual contact with various objects will increase. If the parents note that the child prefers the feel of a certain texture (often this will be human skin), then the child should start with the textures which are similar to the preferred one, and then gradually be introduced to textures which are increasingly different.

Occasionally, despite parents and therapists best efforts, the hand of a multiply handicapped child continues to have no apparent sensation. This is due to extensive damage to the sensory cortex in the area dedicated to the hand, and is seen most often in cases of hemiplegia, where the other hand is relatively unaffected. In these cases, one should check to see if there is some intact sensation in an unexpected area of the hand, such as on the heel of the hand, the back of it, or the wrist, which may be useful.

The hemiplegic child usually holds his spastic arm against his body, with the elbow flexed and the hand fisted. He neglects his side in favour of carrying out all manipulations with the good hand, missing the opportunity for some kind of functional assistance from the spastic arm. Even when the child cannot grasp or feel with his spastic hand, the arm itself can be useful in some circumstances. For example, if the arm is forward, resting on the tray or table instead of being flexed against his side, it can block unwanted movement of a toy while the child plays with it, keep a bowl in place while he eats, or secure a piece of paper while he draws. One method for keeping a spastic arm forward is to attach a short piece of heavy dowling vertically to the tray, with the spastic hand curved around it. Another is to make a wrap-around elbow splint or "gaiter", constructed of several layers of heavy cotton with long pockets into which can be slipped strips of metal. With the elbow thus supported in extension, the shoulder retraction should be reduced, and the arm will easily rest on the table.

d) Disturbed sensation in the feet

Children with cerebral palsy may have disturbance of sensory feedback from their feet and legs, thus interfering with the development of mobility skills especially if they are blind. Some sensation in the feet is retained however, and increased awareness of the limbs, their position in space and the direction and speed of their movement, can be obtained through therapy.

However, there is another disorder, meningomyelocele, in which sensory impairment in the lower extremities is permanent. In this disorder, the congenital spinal defect may result in various levels of paraplegia, and loss of sensation in the feet. Children with this condition almost always have hydrocephalus, which in turn is occasionally associated with visual impairment or even complete blindness. Lack of sensation in the feet can present an enormous obstacle to a blind child when learning to walk, as he can neither see the floor, nor feel it. Sighted children with spina bifida usually wear braces and learn to ambulate using a walker, with vision helping to orientate their feet. Where there is no vision in the above situation, the child's only perceived contacts with the environment are his hands on the walker, and so it is enormously difficult and sometimes impossible for him to learn to move his feet. If braced in standing for daily play periods, he may benefit in terms of increased circulation, stronger bones and prevention of deformity, but a wheelchair may, in the long run, provide a better opportunity for independent travel.

It must be noted that even a small amount of useful vision makes an enormous difference, and so a partially sighted paraplegic child will probably be able to walk.

e) Lack of mobility

The "normal" blind child explores his environment physically, by moving through it, and the sighted, physically handicapped child, who cannot move around, explores it visually. The multi-handicapped blind child can do neither, and so may lack a great deal of information about his immediate world. Initially, parents should be sure the baby is moved to different parts of the house throughout the day, and is introduced to a wide variety of common household objects. As soon as the child is developmentally ready, he should be assisted to move about by himself. Sometimes he can be taught to roll or crawl around a room, and therapists should be prepared to allow less than perfect movement patterns, if this is the only way the child can express his need for movement and exploration. Other children with more severe motor problems will need some type of equipment.

A "Castor cart" allows the child to move about, in a sitting position, close to the floor, and a scooter allows him to move about in prone. Crawlers give support under the trunk for crawling, and there are a wide variety of walkers designed to assist in ambulation. The book "Handling the Young Cerebral Palsied Child at Home" (Finnie, 1978) offers parents a wealth of information regarding different types of equipment, as well as handling, positioning, and generally caring for children with cerebral palsy.

When the need for a piece of equipment is established, parents must be prepared to work through a trial and error approach, along with the child's therapists, until it is properly adapted to suite his special needs. For example, a child may hang off the end of a scooter, and cry, but when a wedge is added to lift his chest, he can propel himself along with his arms, and learns to enjoy the experience. It must be remembered that blind children are often resistant to new pieces of equipment at first. Parents should not give up at the first sign of upset, but on the other hand should introduce the child to the equipment very slowly, for only brief periods at first.

SUMMARY

It has been seen that in order to best help the child with a combination of visual and motor problems, consideration for all developmental aspects, and a flexible approach are necessary. In the past, physiotherapists did not have much knowledge regarding the effect of visual impairment on motor development, but there has been a recent growth of interest, and a new approach to the physical treatment of the visually impaired and multihandicapped child is emerging (Cech and Pitello, 1977, Sykanda and Levitt, 1982). Continued dialogue between therapists, CNIB, workers, Infant Development Consultants, teachers of the blind and parents will result in improved management of multihandicapped children in years to come.

REFERENCES

1. Bax, M.C.O. Terminology and classification of cerebral palsy. Developmental Medicine Child Neurology, 1964, (6), 295-307.

2. Cech D. and Pitello, A. Combining specialties to serve low functioning visually/physically impaired children. Visual Impairment and Blindness, 1977, 439-440.

3. Dellon, A.L. Evaluation of Sensibility and Re-education of Sensation in the Hand Baltimore, Williams and Wilkins, 1981.

4. Finnie, N. Handling the Young Cerebral Palsied Child at Home. London, William Heinemann, 1974.

5. Freeman, P. Understanding the Deaf-Blind Child. London William Heinemann, 1970.

6. Hannah, R.E. and Cottrill, S.D. The Canadian Collar: a new cervical spine orthosis. American Journal of Occupational Therapy, in press.

7. Jan, J.E., Freeman. R.D.. Scott, E.P. Visual Impairment in Children and Adolescents. New York, Grune and Stratton, 1977.

8. McInnes, J.M. and Treffry, J.A. Deaf-Blind Infants and Children. Toronto, University of Toronto Press, 1982.

9. Robinson, G.C. Epidemiological studies of congenital and acquired blindness in children born in British Columbia - 1944 - 1973. Proceedings of the First National Multidisciplinary Conference on Blind Children, Vancouver, 1974.

10. Scranton, P.E., Clark, M.W., McCosky, M.A. Musculoskeletal problems in blind children. Journal of Bone and Joint Surgery, 1978, 60, 3, 363-365.

11. Sykanda, A.M. and Levitt, S. The physiotherapist in the developmental management of the visually impaired child. Child: Care, Health and Development. 1982, 8, 261-270.

12. Warren, D.H. Blindness and Early Childhood Development. New York, American Foundation for the Blind. 1977.

SEXUAL INSIGHT
EXPLORING SEXUAL ISSUES WITH VISUALLY IMPAIRED AND MULTIHANDICAPPED PERSONS

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INTRODUCTION

A congenitally blind nineteen year old man approached the male social worker in an agency for the blind and rather abruptly said, "I can't make it with my girlfriend." The social worker, surprised by the suddenness of this exclamation, was not sure how to respond to it. However, sensing the young man's discomfort, he said, "You sound very distressed about this." The young man picked up on this: "I am ... a friend told me that blind men become impotent ... is that what's happening to me?"

If you were there, what would you say or do now?

Systematic enquiry about a person's sexual life is relatively new in health care and there are many unanswered questions about, for example, how to approach the subject, what to ask, when to ask it, and who should make the enquiries, with what background training.

The purpose of this paper is to illuminate the roles of health care workers in exploring sexual areas with visually impaired and multihandicapped persons.

The paper is divided into several parts. First, "sexual areas" of daily living will be delineated; second, "sexual issues" will be portrayed; third, "sexual enquiry" will be illustrated; and finally, professional implications inherent in exploring the sexual areas will be discussed.

SEXUAL AREAS

A twenty-three year old congenitally blind woman volunteered to discuss the sexual aspects of her life. When she arrived at the interview, her first question was, "Okay ... what are

we going to be talking about ...?"

The dictionary definitions of "sex", "sexual" and "sexuality" usually include "gender"; "gratification," and the urge for it; the "character" of being a male or female; and one "method" of reproduction, the "sexual" versus the "asexual" type (1).

Obviously, visual cues have a great deal to do with any of these manifestations, attributes, activities or experiences. However, a health care worker requires a set of practical criteria for defining the sexual areas of daily life and for estimating the sexual functioning capabilities of an individual. For example, the clinicians at a Sexual Health Service for the disabled use the following seven categories for establishing a person's sexual functioning status (2).

1. Sexual Response Status reflects the ability of the patient to experience the normal cycle of physiological events in sexual response.

2. Sexual Activity Status gives indication of the available motor functions which might be used for embracing, intercourse, and related activities.

3. Sexual Organ Status gives evidence of the anatomical integrity of the genitalia and the manner of managing menstrual hygiene, and bowel and urinary continence.

4. Fertility Status reveals the patient's ability to procreate and, when indicated, the contraceptive method available to the patient.

5. Sexual Interest Status reveals the patient's preoccupation with sex related issues.

6. Sexual Behavior Status gives information about the patient's social skills for courting and sexual activities.

7. Sexuality Status describes the degree to which a person uses sex practices as a way to prove manhood or womanhood.

These categories may be regrouped under other headings, to ensure that they make sense to younger persons and their parents. For example, parents of the disabled often worry that nobody will want their child as a future lover, husband, or wife; or that their child will never have the opportunity to become a parent. The headings that might reflect these

concerns could be "getting into the social mainstream" ("marketability"); "partner selection" ("courting"); and "sexual practices and experiences" ("doing").

One reason for concerns is that many persons look at "sexual" behaviors and experiences as "performances" in the social setting. Not infrequently an individual, the family, and friends, may aim at "performance standards" which are based on misinformation or which may have been formulated in the absence of contemporary knowledge. Failing to measure up to a real or imagined standard in the various sexual areas may be frightening to the individual and to the family. For example, a person who cannot perform to some perceived standard in the sexual practices or "doing" area, may believe that he or she is not fit to be a partner and, therefore, he or she will be "unmarketable" as a husband or wife, or as a father or mother. Nor unreasonably, such a fate may signal prospects of a lifelong isolation. Conversely, a person may be declared by others as "unmarketable," because of unusual appearance, unpleasant mannerisms, or physical disabilities. A person so singled out may never be offered the chance to practice the skills necessary for the "courting" and "doing" activities.

When the twenty-three year old congenitally blind woman (who volunteered to give information about her "sexual life") heard the description of some of the "sexual" areas she said, "... I guess I am now beginning to feel that I am 'marketable.' I have a good job, and people say that I look okay ... I had surgery on my eyelids. I don't think I have much in the way of mannerisms any more ... My father used to yell at me every time I looked up at the ceiling or nodded my head. But till recently, I did have a terrible problem. I really did not believe that I could get into these "courting" or "doing" situations that you talk about. For many years I had bad constipation. Because of this, I had a lot of rectal examinations when I was a child. I came to believe that my whole private area was abnormal. As I grew older, I did not dare to have anyone, including doctors, touch or look at my genital portion. I had strong sexual interest and I could make myself come to orgasms, but I felt that I must be so ugly down there that nobody would want me. So I just pulled myself off the 'market' and lived in my fantasy world. Last year, after talking to another woman, I gathered up enough courage to go to a doctor. He gave me a clean bill of health. I know that I lost time in learning what to do when with another person. But I feel that maybe I do have a chance to be like other people".

SEXUAL ISSUES IN THE VISUALLY IMPAIRED PERSON

1. Epidemiological Consideration

Sexual problems listed in the medical literature include gender identity disorders (for example, transsexualism); paraphilias (for example, child molesting); sexual disinterest, and sexual dysfunction (erection, ejaculation, and orgasmic problems in men, and in women arousal, and orgasmic difficulties and vaginismus) (3). The incidence and prevalence of these problems in the general population is not fully understood; reliable epidemiologic information about such problems in the visually impaired population or in the population of visually impaired and multihandicapped persons is non-existent.

2. Literature

Sexual maturation is believed to be early in blind women. For example, a study of congenitally blind girls indicated that they reach menarche at an earlier age than a comparable group of normally sighted girls (4). Another study suggested that totally blind women who had no light perception at all, reached menarche at a mean age of almost one year earlier than blind women with some light perception and sighted women (5). Once menstruation started, the ovulation symptoms and signs in a group of blind women were similar to those recorded by sighted women (6).

There are few studies about the Sexual behavior patterns of blind persons. In a study of thirty-nine women totally blind from birth or by the age of ten, the mean age of sexual intercourse was twenty-one years compared to seventeen for sighted women. Significantly, six of the blind women never had sexual intercourse, while in the matched group of sighted women, all had intercourse. The mean age of these women was 30.4 years (7). A study of legally blind adults, ranging in age from twenty-three to ninety-three years of age, indicated that the blind, especially those in the younger age group were less likely to be married than their sighted counterparts. One explanation for this is that blind persons might be less "marketable" because they are poorer and less educated in comparison with sighted people (8). Studies of blind children describe mannerisms such as eye pressing, light gazing, rocking, and head turning, which if carried into adulthood may be distrubing to others (9).

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With regard to sexual problems, one study reported that of fifty-four men whose blindness antidated puberty, fifty-two experienced erection difficulties. According to the study, sexual interest of these men was not disturbed (10). The nature of the erection difficulties was not clarified in this study. This is unfortunate because there are various types of erection problems: for example, one is the situational type of erection difficulty in which the person may well have full erections in some situations but not in others. The situational erection problem is believed to be based on fears of failure (performance anxiety) or on fears of the consequences of being involved in the sexual act. It is not clear at all how visual impairment would be a factor in the development of this type of erection problem. Another type of erection problem is "global," meaning that the erection difficulties occur under all circumstances. In some instances of acquired blindness, the cause of the loss of vision has also caused such sexual dysfunctions as erection, ejaculation, and orgasmic difficulties. Diabetes, multiple sclerosis, and brain tumors are examples of these conditions. The reaction to adult onset blindness may also include depression, impaired self-esteem, and social withdrawal, which may contribute to sexual disinterest and dysfunctions.

3. Clinical Experiences

Close to one thousand disabled persons between the ages of seven and eighty-two years, and about five hundred partners and parents were referred to a Sexual Health Service since 1975.* Sixty percent of these patients were spinal cord injured; the others included persons with stroke, cerebral palsy, head injury, multiple sclerosis, meningomyelocele, and various other orthopedic and neuromuscular disorders. Four young persons were blind or visually severely impaired; three of them also had other disabilities. Their case histories will help to illustrate the when, what, how and why of a sexual enquiry.

Patient #1

A nineteen year old congenitally blind man was unable to have erections in a situation when he was called upon to enter into the act of sexual intercourse.

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Patient #2

A nineteen year old woman with acquired brain damage and associated right hemiplegia, speech defect, and visual impairment was suffering from sexual anxieties. She said: "nobody will want me; how will I know if a man loves me or pities me?; I had orgasms before and they were strong. I don't think I would dare to have an orgasm now, I am afraid it might cause more damage to my brain."

Patient #3

A sixteen year-old visually impaired boy with cerebral palsy and some mental deficiency wished to experience sexual sensations, but he did not know how to stimulate his penis.

Patient #4

A fifteen year old visually impaired girl with cerebral palsy experienced heavy menstrual periods. Because of her severe physical disabilities, she was unable to look after her menstrual hygiene. Part of the time her father had to change her menstrual pads. The parents were wondering about a hysterectomy as a way of eliminating the menstrual problems. They felt this would be a good solution to birth control too. They could not visualize their child as ever becoming a mother.

SEXUAL ENQUIRY

A sexual enquiry has five fundamental purposes (11).

1. To let the patient know that "sex is spoken here" (ie., it is not a taboo subject); and to establish trust and rapport.

2. To help the patient understand what the sexual areas are.

3. To help the patient describe concerns relevant to these areas. (For example, impotence, no partner, infertility, or poor self image).

4. To clarify the nature of the concern. (For example, the onset, duration, or the course of the problem's development).

5. To establish significance of the concern. (For example, is it a threat to the patient or to the relationship? What is the degree of sexual interest and opportunity? What other stresses are present in the patient's life? Has other help already been sought?)

The significant factor underscoring the need for sexual enquiry is that the professional is still largely dependent on the sex functioning history from the patient (and the partner) to sort out the nature and the probable causes of the sex problems. This is so, partly because of the lack of specific tests and partly because one cannot accurately predict which patients will develop concerns or problems.

1. WHEN TO ENQUIRE

Patients' "sexual" concerns come to the team members attention in one of three ways (12). The case histories of the four visually impaired young persons will illustrate these ways.

Directly

Patient #1 openly expressed a complaint that was clearly sexual. The ninteen year old congenitally blind person said to the social worker, "I can't make it with my girlfriend."

Indirectly

Patient #3 and #4 used expressions or described situations indicating preoccupations with sexual questions, concerns or problems. For example, Patient #3, the sixteen year old congenitally blind boy with cerebral palsy and mild mental retardation, asked the teacher in a special school, "Do I have seeds in me?" When the teacher said that she was sure he did, the young man asked, "How would I get it out?" When the teacher elected not to answer this question, the boy asked her repeatedly for the next week, "How do I get it out?" The teacher consulted other team members and the decision was made to contact the parents with the suggestion that "sexual counselling" might be of value.

Patient #4, the fifteen year old blind girl with cerebral palsy and good intellect, enquired from the occupational therapist about menstrual care. "So far my father has helped me putting the pads on, but I would like to do it myself ... could you teach me ...?" The parents were contacted in this situation. The inquiry about hysterectomy as a possible solution was brought up by the parents in their meetings with the social worker. Referral to the physician, and then to the sexual health service followed.

In response to direct enquiry

Team members might feel that a person with a certain condition is sure to have sexual worries even though such concerns have not yet surfaced. For example, Patient #2, the nineteen year old woman with severe visual impairment, hemiplegia, and speech disorder was a well person with normal vision two years before. Walking along late one night, she was attacked, raped, beaten, and left for dead. Now, well into her rehabilitation, the staff felt that something should be done to explore her sexual feelings. "Does she think she is 'marketable'? Will anybody court her - will she what to be close to anyone? Will she be able to do sexual things and have, for example, orgasmic experiences?" An enquiry uncovered significant concerns in several of the "sexual" areas.

2. WHAT AND HOW TO ASK

The following conversations illustrate some of the areas of enquiry and the interview techniques that might help in achieving the enquiry's purposes.

Patient #1

The nineteen year old congenitally blind man approached the social worker saying, "I can't make it with my girlfriend." The social worker, who was new in the job, did not know what he should do or say, but he sensed the young man's distress.

Social Worker:	"You are very distressed about this." (acceptance)
Patient:	"I am ... I guess, I'm not going to be a man ... a friend told me that blind men are impotent ... is that true?.
Social Worker:	"I never heard of this ... I don't really know the answer ... but I want to help you with this problem ... I think I know the person who could answer your question ..." (declaring limitations but offering help)
Patient:	"I don't want to spread this around."
Social Worker:	"I understand how you feel ... I will have something for you by tomorrow ... But before you leave, can I ask you if you have a girlfriend now?> (permission)
Patient:	"No."

Social Worker:	"No, 'I can't ask you; or 'no', no girlfriend?" (clarification)
Patient:	"She was someone I knew sometime ago. She is out of the picture."
Social Worker:	"Do you want to talk about this a bit more?" (acceptance)
Patient:	"No, not today. I want to know about impotence."
Social Worker:	"Okay, I'll call you in the morning ... but if I miss you, call me back tomorrow afternoon." (letting patient set the pace; summarizing the agreement for further steps.)

The social worker was new to the agency and did not know what the prevailing administrative approach to sexual discussions was. In some institutions this subject is avoided; at some others it is considered only if the patient or client makes a specific effort to bring it up; yet at other places, the staff is encouraged to explore this area. In any case, this social worker had no previous experience in sexual assessment or counselling. However, recognizing the sexual nature of the young man's enquiry, he had no hesitation in accepting the patient's concerns. He quickly defined his limitations to the patient and offered his assistance in a search for other competent help. He asked one question about the patient's social situation; when this was obviously not wanted, he made a competent referral.

This interaction represents the basic approach to a patient with sex related concerns: to let the patient know that "sex is spoken here" (ie., it is not a taboo subject); and to establish trust and rapport; and to seek out more experienced help when the professional reaches the limits of his or her expertise.

Patient #2

The nineteen year old woman with the head injury and the resulting hemiplegia, visual impairment and mild speech defect was approached by the occupational therapist. The staff decided at a team meeting that the occupational therapist was the closest person to this young woman to explore her sexual perspectives.

O.T.:	"Jane, you might be going home in a few weeks."
Jane:	"I'm looking forward to it."
O.T.:	"I saw your boyfriend coming to visit you. Is he going to help you to move?" (This is an attempt to move towards the sexual area.)

Jane: "What boyfriend? I haven't seen him for two weeks now!"

O.T.: "Can I ask you what's happened between the two of you?"

Jane: I'd rather not talk about it ... who wants a blind cripple..."

O.T.: "Anyone who knows you ..." (Attempt at support and reassurance.)

Jane: "Haw ..."

O.T.: "Jane, can I ask you a bit more about this situation?" (permission asking)...

Jane: ...(Quiet)...

O.T.: "It sounds to me that you might have some concerns about Bob ... or other boyfriends." (Moving into the "courting" and "marketing" areas.)

Jane: "I think that I am going to give up on that."

O.T.: "On what?" (Clarification)

Jane: "Boyfriends, sex, getting married, having a baby." (She is now crying)" ... well, I can hardly see. My arm is useless."

O.T.: (Listening quietly)

Jane: "Maybe I could talk to you later ... I have to think about these things ... maybe when I am at home ..."

O.T.: "I would like it if you would call me ..." (Open for further talk, but without promise; in the long run Jane will have to work out her own lifestyle.)

This conversation enabled the professional to bring the conversation around to sexual concerns and to indicate to Jane her willingness to continue the discussion ("Sex is spoken here"). The right timing for the initiation of such a conversation is highly individual. For example, in one survey of acute spinal cord injured patients about one third of the patients recalled that an introduction of the sexual topic within a few weeks of the injury was very helpful. These patients said that they were worried about their sexual losses, but did not dare to ask and did not know where to turn for help. About one third felt that introduction of the topic, even in the first few months of the injury, was too early; yet others did not have a clear opinion (13).

In this instance, Jane called about six months later to say that she had something to talk about. Apparently, Jane met another young man.

Jane: "I feel really good about him ... He doesn't seem to mind my arm or leg."

O.T.: "Tell me a bit more." (Establishing rapport; letting patient set the scene.)

Jane: "Can I talk to you about sex?"
O.T.: "What would you like to talk about?" (Sex is spoken here: clarifying)
Jane: "Can I have a ... climax?"
O.T.: "Can I ask you some questions first? Like what you had before or since the injury?" (Asking permission for further exploration)
Jane: "I had it before ... like a peak ..."
O.T.: "And since the accident?" (Clarification)
Jane: "I was turned on for sure with Jack ... that's my new friend. But no climax."
O.T.: "Can I ask some more questions?" (Sensitive area; asking permission to proceed)
Jane: "Sure"
O.T.: "Some persons come to climax with intercourse, others with their hands or with the partner's help ..." (This list serves to reassure the patient that there are many ways ... and prepares the patient for the next question.) "What was the best way for you before?"
Jane: "I guess my hand ... that was the only way, but I never told this to anyone."
O.T.: "Many women find that using their hand helps them to come to an orgasm." (Reassuring on the basis of correct information.)"
Jane: "Really? ... I thought it wasn't quite right."
O.T.: "Have you tried it lately?"
Jane: "I haven't dared ... since I had my injury ..."
O.T.: "Any specific concerns?" (Clarifying)
Jane: "I don't know - I guess I am afraid my brain might get shaken up ... maybe my eyes will get worse..."
O.T.: "You are worried that the climax might do something in your head?" (Checking out if this is the source of the concern.)
Jane: "Yes, something like that ..."
O.T.: "This is a realistic question ... and I really don't know the answer ... but this is something we can find out for sure ..." (Defining limitations in knowledge, but at the same time accepting patient's concern and encouraging a search for solution.) "How would you feel if I would arrange for a visit with someone who deals with these issues...?"
Jane: "Could they also talk about contraception? I used to be on the pill, but I don't know if it's good for me now..."

In this case, the occupational therapist collected a great deal of data from the patient. She was accepting in her approach, offering information, and crystallizing the patient's main concerns. She also defined the limits of her expertise to the patient and moved the discussion out of the

realm of a friendly talk, into the area of legitimate rehabilitation procedure.

This interaction illustrates several components of an initial enquiry. These include establishing trust; helping the patient describe her concerns; beginning to clarify the nature and onset of the problem; gauging the significance of the concern and the degree of sexual interest and opportunity and triggering expressions for help in other areas.

Patient #3

The sixteen year old boy with cerebral palsy, congenital blindness, and mild mental retardation, was repeatedly asking the teacher about "seeds" and how these may come out of his body. The teacher did not feel comfortable with discussing this and she approached the Sexual Health Service for help. The Sexual Health Clinician thought that perhaps the boy did not know how to, or could not, stimulate himself adequately. The clinician felt that a low-key approach would be important here; perhaps the parents had strong feelings about masturbation. The teacher and the clinician agreed that the social worker should invite the parents for a discussion. Only the boy's mother came to the meeting.

Mother: "He has been asking this at home too, and I didn't know what to tell him. My husband told him to rub himself, but I don't think he can. His hands, the way they are, ... maybe they don't fit quite around it ... we could use some help ... my husband says maybe the boy should have some release ... it might be good for his health ... is this the same for other blind boys?"

Worker: (There are so many questions here that she does not know how to react to the mother's concerns. She decides to clarify the situation.) "Have you seen him touch his penis?" (uses specific expression to help the mother also become more specific.)

Mother: "Well, he gets erections, I see that when he is in the bath, but haven't seen him do anything ..."

Worker: "I know he is able to hold on to things, so that wouldn't be a problem ..." (Talking about masturbation as a technical activity eases the discomfort.)

Mother: "I don't know ... maybe he is not doing it long enough ... I will have to talk to my husband ... but this has been on our minds too, so I am glad that you brought it up ... I guess I am worried that if he starts to do it maybe he won't stop."

Two months later the teacher mentioned to the social worker that the boy had not been saying anything about "seeds". Four months later the mother came to see the social worker for another matter. The social worker enquired about the self-stimulation situation. The mother said, "That's my husband's department, but I think it's okay now ... after I talked to you, my husband thought too, that John wasn't touching himself long enough. But we didn't know how to show it to him ... but one day my husband had this candle in his hand and he said to John, 'You know how your peepee thing gets hard from time to time? Well, you can put your hand on it like this and just move your hand up and down like this, but you have to do it for some time, and then some of the seeds might come out...' I was really worried that he might do it all over the place, but I haven't seen him doing it and my husband says it's okay ..."

In this case the teacher recognized her limitations but was able to "refer" a problem situation to another team member, the social worker. The social worker involved the parents in such a way that the mother was reassured of the appropriateness of the discussion. The social worker's support here helped the parents to become the "treatment team" without causing much fuss. At the same time, the relationship between the social worker and the family has become stronger. The Sexual Health Clinician was involved here only as a team member and back up resource.

Patient #4

The fifteen year old visually impaired girl with cerebral palsy wanted to talk to the occupational therapist. The girl was in her wheelchair and one of her "helpers" guided the chair into the room

Girl: "Claire (the helper) thought I should talk with you ... I have heavy periods and I can't leave home when I have the periods. My mom is working and so far my father has helped me putting the pads on, but I would like to do it myself ... Claire says it's not right for any father to do it ..."

O.T.: "I'm sure glad you came by to talk about this (reassurance). Have you asked other people about your period?" (O.T. does not want to give contradictory messages).

Girl: "My mother said she is going to take me to the doctor."

O.T.: "Can I ask you a few questions about the periods?"

Girl: "I started about two years ago. Then I stopped having them for a while. They came back a few months ago ... now I am wet for several days, maybe ten days ... Mother says I ruined my best pants ... I wear these big pads now ... my dad lifts me up and changes them. I can't pull them out myself."

O.T.: "Before we do anything, how would you feel if I would talk to your mom or dad to find out when this will be checked out with the doctor? Then we will work out something?"

The occupational therapist met the mother.

Mother: "This has been a terrible problem. Somedays we do nothing but wash clothes. I want to ask the doctor about removing her uterus. I don't suppose she will ever need it ... she could not be a mother ... how would she look after a child? I am also afraid ... she is so friendly ... somebody might take advantage of her ... a hysterectomy would fix all that."

O.T.: (Recognizing that the mother has several agendas). "Well, first things first. The doctor will make an examination ... has Joanne been examined before?"

Mother: "I never even thought of that. Joanne knows what menstruation is about and where babies come from, but come to think of it she has not had any exam down below."

O.T.: "Maybe we could prepare her for that."

Mother: "I don't know. How would you do that? I'm not even sure how I could tell her about it."

O.T.: "Well, maybe we could ask her what she wants to know."

Mother: "That would be good!"

O.T.: "She might ask about other things too ... sometimes when we talk about a pelvic exam, girls want to know about sexual things too. How would you feel if we talked about those too?" (permission)

Mother: "I suppose I should do that, but you know, her father is not so well and I have to work and we have two other younger children. There isn't time. I don't mind, she is a bright girl "

O.T.: "I might ask one of the other team members to help me. She is very good with sexual questions. May I ask you who your doctor is? Perhaps I could call the nurse and find out how they will examine Joanne."

Mother: "I never thought of that. Sure. Here is the number. She is a new doctor. We have just changed."

The occupational therapist called the doctor's office and learned that they were not used to examining blind or disabled persons. They had a standard examining table with stirrups. The O.T. left her name in case the doctor wanted to call back. The doctor called the next day and wanted to know about Joanne's physical abilities: "Could she get on the examining table and open her legs for a pelvic examination? What does a

blind person know about her body?"

The occupational therapist and the Sexual Health Clinician met Joanne the following week. She already knew about "getting a pelvic exam."

O.T.: "In what way could we help you to make this a nice occasion?"
Girl: "I don't know what I am supposed to do."

Keeping Joanne's clothes on, the two workers went through the practice transfer from chair to an examining table, and a pelvic examination position. They found that Joanne's legs went into a spasm and her knees closed rapidly, but after applying gentle, steady pressure on the knees, the spasm subsided. The doctor and the nurse could probably manage those spasms.

Girl: "What's the doctor going to see?"
O.T.: "What names do you use for the various parts?"
Girl: "I know there is the hair, and then there is the hole, but I don't know what it is called, and then there is something you can rub and it feels good..."

In this case, the occupational therapist first established a trust relationship with the patient and the mother. Then she defined the immediate significance of the problem to the patient, the mother, and to the doctor. To the patient the issue was: "Could I change my pads myself." To the mother the present issue was a hygienic matter, but the ultimate issue was that her daughter was going to be a mature woman soon - but without a future as a mother. The doctor was interested in the technical aspects of the physical examination. The occupational therapist focused on the immediate situation and helped to prepare the patient and the doctor for the pelvic exam. She used a practical method to find out what Joanne's physical limitations were and how these could be overcome in a doctor's office. Having first obtained permission from the mother, she and the Sexual Health Clinician answered Joanne's questions. They used teaching aids which were suitable for Joanne and they left the door open for her to come back for more information.

This case illustrates how the sexual enquiry may be extended into a "physical examination" and how this, in turn, may become an educational session.

3. USEFUL INTERVIEW TECHNIQUES

The conversations highlighted a few techniques which are especially useful in sexual enquiries (14).

Ask for permission. Whenever a new sexual area is about to be discussed, a good approach is to ask, for example, "Can I ask you a question about your relationship?" If the patient says, "No, I don't want to talk about it: the worker can safely reply, "I am glad I asked you first. I would not want to invade your privacy." While the worker should stop this line of questioning, the reason for the patient's negative reaction may need to be further investigated. Most commonly, the patient is not ready yet to discuss certain issues. This was the situation when the head injured, hemiplegic, visually impaired young woman was first approached. The case of the fifteen year old girl with menstrual problems illustrated the need to obtain permission also from the parents.

Be specific. Most patients and parents find it easier to deal with well stated questions than generalities. For example, in the case of the sixteen year old boy described earlier, the worker's use of the word "penis" triggered the mother to say something about her observations about erection.

Avoid irrelevant questions. A useful rule is to ask oneself, "Why did I ask this? Could I explain the reason for my question if the patient challenged me?" If the answer is yes, the question was not irrelevant.

Start with reassurance. In the case of the nineteen year old head injured woman the worker said, "Many women find that using their hand helps them to orgasm." This information served as a guide to statistical norms regarding this activity. The patient could say to herself, "Ah, I am not abnormal."

Proceed from least sensitive to more sensitive areas. In the case of the nineteen year old head injured, the worker began her exploration of the sexual areas by making reference to boyfriends and relationships. The conversation can escalate from there to more sensitive areas.

Use language that is clear to the patient. The language can be medical, slang, or earthy, depending on the patient's needs and the worker's comfort. People somethimes say, "organism" meaning orgasm or "pee-nuts" instead of penis.In these instances, correction may be embarrassing but letting the person know that "not that it makes any difference, but here we usually say orgasm" may be helpful.

IMPLICATIONS TO PROFESSIONALS

1. The Specialist's role

People approach nurses, therapists, psychologists, social workers, brace makers, and even housekeepers with their sex related concerns. If there is a specialist backup, both patients and the team members might feel more at ease discussing sex issues. What can a "nonspecialist" expect from a "specialist?"

The main objectives of a specialist in the sexual area include: clarifying the main concerns; establishing the patient's objectives; determining the patient's and partner's physiological, social and personal potentials and resources; helping the patient to reformulate the sexual objectives in realistic terms; and carrying out relevant treatment techniques.

The specialist usually supplements the historical enquiry with a physical examination and investigations. The physical examination serves at least three purposes: estimating the musculoskeletal abilities for various sexual activities; evaluating the neurological capability for sexual responses; and inspecting the hygiene of the genital area. Investigations may include determination of sex hormone levels; fertility investigations; erection capability measurements; and other relevant pyschological, social, or medical investigations.

The specialists' treatment approaches are based on the results of the sexual evaluation and on concepts of the causation and evolution of the problem. The approaches can be visualized as psychological (talk and guidance oriented), medical (involving medications), physical (using external devices, appliances), and surgical (using internal devices or other operative procedures). The combination of these approaches may be employed from time to time and the contact with the specialist may be short-term, or long-term, regular or sporadic, open-ended or time limited. Some of the treatment approaches may require involvement of the partner and sometimes a group format is used.

There are no treatment methods specifically designed for blind persons with or without other disabilties. There is not enough known yet about the evolution of sexual life patterns in this group. The treatment approaches are selected and modified in accordance with the realisms of the person's situation. This means that the diagnostic, prognostic, and treatment activities are still based on educated opinions.

For example, in the case of the nineteen year old head injured woman, the clinician's encouragement helped the young woman to begin to experiment with herself and experience increasing arousal on self-stimulation, eventually to the point of orgasm. This helped the young woman greatly and she did not suffer any ill effects. However, the clinician's advice was not based on knowledge of the physiological reaction in the brain following an injury.

In the case of the sixteen year old boy, who presumably began to stimulate himself adequately enough to experience an orgasm, the clinician did not know whether this may become a preoccupation to the young man. While information is available about masturbation habits of able-bodied young persons, comparable information in physically disabled persons with or without visual impairment, and with or without mental deficiency, is not available.

In the case of the nineteen year old congenitally blind man with concerns over his ability to accomplish the sex act, no specific "cure" was possible. The clinician offered information about the functioning of the penis and about ways of "courting" and "doing". However, all this was done in the abstract, without a partner providing the reality of a situation. (Was he really clumsy? Was she interested? Would she like to be with him again?) If the erection problem had been related to the complications of, for example, diabetes, then the use of a penile prosthetic device might have been considered. This device, inserted surgically into the penis, provides a reliable but artificial erection. A visual impairment would not be a contraindication to this surgical procedure. However, while the surgical approach is being used with increasing frequency in the management of erection disorder caused by medical conditions, the long-term personal and social outcomes are not really understood.

The specialist has a two way relationship with other professionals. For example, the specialist asked the referring social worker for assistance in bringing the nineteen year old man into social situations where his "marketability" could be developed. Perhaps then, a partner would surface and the condition would either be resolved naturally or perhaps the new partner might be willing to participate in some form of joint discussions.

In the case of the fifteen year old girl with the menstrual problems, the specialist was helpful to other team members in pointing out priorities in the management of complex issues. There the first priority was to find out about the reason for the changes in the menstrual flow pattern. This in turn,

brought into focus the specific needs with regard to the physical examination. The other issues, such as the question about the father's role in changing menstrual pads, the role of the hysterectomy in the long range plans for the menstrual management, or the motherhood capabilities of the young woman were identified, but left for the moment. The whole picture might be different once the medical problem is settled.

2. The Nonspecialist's role

The clinical examples also suggest that team members exploring the sexual areas may find themselves in the roles of trusted persons, consultants, teachers and practitioners of preventive intervention (15).

For example, the sixteen year old boy and his mother identified the social worker as their "consultant." In the case of the nineteen year old man with erection problem, the sex clinician reached out for the social worker's expertise in socialization programs. In these "consultations" the patients and the sex clinician expected the workers to put aside their personal behavior code and accept the patients' needs and concerns as legitimate. The fifteen year old girl and her mother looked at the occupational therapist as a "teacher" who prepared them for a pelvic examination. In this case, and also in the case of the nineteen year old woman with visual impairment and hemiplegia, the occupational therapists also practiced preventive intervention. In both instances the worker acted upon their perception that certain sexual concerns might be hidden, or that the patients are not well enough informed about some aspect of their sexual functioning.

All workers involved in these case examples came across to the patients as trustworthy individuals. Even the sixteen year old boy who repeatedly asked about the "seeds," turned to his teacher because he was a "trusted person." In that case the teacher felt uncomfortable to deal with the situation but reached out for others who were better equipped to assist. Similarly, the social worker recognized his limitations when he was approached by the young man with erection concerns and he made a carefully prepared referral to more qualified personnel.

These case examples also indicate that health care workers moving into the sex-related "consulting", "teaching" and "preventive" roles may require certain attitudes, some new knowledge and an expansion of their already existing interviewing skills. Each of the case examples points to a need for an accepting attitude. Professionals can acquire such an attitude if they accept "sex" as much more than

"intercourse." The concept of "sex" as having "marketing," "courting," and "doing" dimensions may help in broadening one's views.

Knowledge of the basics of sexual and reproductive physiology and of contemporary sexual practice patterns is essential for all professionals. Information in these areas may be obtained in numberous publications. There are two types of interview skill requirements: one, to clarify information and the other, to give information. The case examples illustrated various degrees of "clarification." The techniques are not different from other instances of interviewing.

Giving sexual information to visually impaired persons may challenge the inventiveness of the professional. The use of objects or models is an obviously valuable method in providing information to "ordinary" persons. A blind person may find, however, that the texture and temperature of a rubber or plastic model has little in relationship to the real body part. For example, the twenty-three year old blind woman who volunteered information about her sexual experiences said that she needed dozens of touch experiences with the rubber model before she built for herself a conceptual picture of male genitalia. Even then, she was unprepared for the sensations which she eventually derived from the responsiveness of the real organ.

3. Is it worth it

Professionals often ask: "Is it worth it to bring up the sexual issue? Maybe we are raising expectations that can never be fulfilled? Ignorance is bliss!" The case examples in this paper clearly illustrate that sexual concerns and problems of a wide variety were already causing internal upheavals in these young persons, their partners, their parents, and their professional attendants.

Following even brief professional interaction, each of these young persons acquired an extra measure of trust in a health care or social worker. Two of the young persons developed a closer relationship with their parents. The nineteen year old man gained sexual knowledge and social skills which will help him in the future. The nineteen year old woman with hemiplegia developed a rich emotional and physical experience with another young person following clarification of her anxieties. The fifteen year old girl was placed on medication which controlled her menstrual flow to the point that she did not need her father to change her menstrual hygiene pads. Her parents also felt better because their immediate concern about their child's sexual safety was relieved. The family also

began to look at their child as a possible mate to someone. This may or may not be realistic but hitherto it was not even considered as an option.

The sixteen year old boy acquired self stimulation skills. Equally significant, however, is that his parents have become closer to each other through discussion of his sexual needs; and their trust in him increased as he demonstrated his ability to limit his self stimulation to private moments.

These achievements are contributions to the very essence of the habilitation and rehabilitation process.

REFERENCES

1. Charles Scribner's Sons.: Sex Information & Education Council of the U.S.: Sexuality and Man. N.Y., 1970

2. Miller, S., Szasz, G., Anderson, L.: Sexual health care clinician in an acute spinal cord injury unit. Archives of Physical Medicine and Rehabilitation, 1981. 62: 315 - 320.

3. Diagnostic and Statistical Manual of Mental Disorders (Third Edition). The American Psychiatric Association, 1980.

4. Magee, K., Basinka, J., Quarrington, B.: Blindness and menarche. Life Science, 1970. 9: 7 - 12

5. Zacharias, L., Wuvrtman, R.J.: Blindness; its relationship to age at menarche. Science, 1964. 144: 1154 - 1155.

6. Sans, L.J.: Ovulation symptoms and ovarian function in blind women. Fertility and Sterility. 1977. 28: 3, 277 - 278.

7. Welbourne, A., Lifschitz, S., Selvin, H., Green, R.: A comparison of the sexual learning experiences of visually impaired and sighted women. Journal of Visual Impairment and Blindness. 1983. 77: 6, 256 - 258.

8. Feinman, S.: The blind as ordinary people Journal of Visual Impairment and Blindness. 1978. 72: 6, 231 - 238.

9. Jan, J.E., Freeman, R.D., Scott, E.P.: Visual Impairment in Children and Adolescents. N.Y., Grune & Stratton. 1977; pp. 239- 255.

10. Blindness believed to impair sexual functioning. Hospital Tribune. September 24, 1973. p. 35.

11. Stevenson, R.W.D., Szasz, G.: Diabetes and sexual dyfunction. Beta Release. 1984. 8: 3, 5 - 7.

12. Szasz, G. "Sexual Health Care."In: Zejdlik, C.M., editor Management of Spinal Cord Injury. Belmont, Ca. Wadsworth Health Services, Wadsworth Inc., 1983.

13. Szasz, G., Miller, S., Andnerson, L.: Sexual rehabilitation of the acute spinal injured. In: Medical Sexology. The 3rd International Congress. Eds: R. Forleo and W. Pasin. Littleton, Mass. PSG Publishing, 1980.

14. Stevenson, R.W.D., Szasz, G., Maurice, W.L., Miles, J.E.: How to become comfortable talking about sex to your patients. Canadian Medical Association Journal. 1983. 128: 797 - 800.

15. Szasz, G.: Sexuality curriculum for the physiatrist, physiotherapist, and occupational therapist. In: Rosenzweig, N., Pearsall, F.P., Sex Education for the Health Professional. N.Y., Grune & Stratton, 1978.

RECONCEPTUALIZING THE DEVELOPMENT OF YOUNG BLIND CHILDREN

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I shall first discuss what we mean by conceptualizing and why we spend our time writing about it. Then I shall talk about why we find it necessary to reconceptualize the development of young blind children. I can only outline our positions here, but refer those interested to our articles in the Journal of Visual Impairment and Blindness throughout 1984.

Conceptualizing

The position I shall present in outline today has been developed over several years and underlies all my work, written and applied, dealing with the development of young blind children. Because I believe profoundly in the necessary interaction of practice and conceptualization, I tend to refer to our type of thinking as clinical conceptualizing. The stage which we have reached is still exploratory, and does not necessarily show originality. We try to make explicit what is normally implicit, on the grounds that what you do not realize controls you, whereas the ideas of which you are aware can come under your control and are much more accessible to change.

Conceptualizing is one of those seemingly academic words which are suitable for journal articles but not for the real world, but we cannot treat the activity of conceptualizing as academic or remote, because for us conceptualizing is at the core of human actions. For the moment, let us simply describe a conceptualization of some phenomenon - a belief, a technique, an object - as the total of all our understandings, ideas and perceptions, gathered up in some structure that hangs together. Some examples may help to make the point.

Self-concept is a conceptualization. We conceptualize people in terms of the way they see themselves, as Dean Tuttle described in his paper yesterday. He focused on the notion of the self-concept in its most focused form, the cognitive component, and also on the affective component, which he called self-esteem. We should wish to stress the third

component of any conceptualization, the conative component, the directing-to-action function. Conceptualizations are not merely convenient ways of clustering information, ideas or attitudes, they are generators, they drive us to action. Thus, one kind of conceptualization is a prejudice. To perceive someone in terms of skin colour, religion, political belief or physical difference simplifies making decisions about how to act towards that person. Gordon Allport, in his classic work, "The Nature of Prejudice", cites an experiment conducted in Ontario by a Canadian social scientist, S.L. Wax. He wrote two letters to about one hundred resorts in the early summer season, asking for room reservations on the same dates and mailing the letters to each resort at the same time. One letter of each pair was signed "Mr. Greenberg", the other "Mr. Lockwood". 95% of the resorts replied to Mr. Lockwood, and 93% offered him accommodation, whereas 52% replied to Mr. Greenberg and 36% offered him accommodation. Somewhat redundantly, Allport commented that "the decision was obviously made not on the merit of the individual, but on Mr. Greenberg's supposed membership of a group".

Prejudices and stereotypes are the extreme forms of categorization, and we routinely categorize in order to make some sense of our world and to find a way to act on it. Categorization is functional and ceaseless, as is acting on it. When a Neanderthal man first encountered a sabre-toothed tiger and got away, he probably had little doubt that this creature belonged to the category of "inappropriate company". When he next encountered the tiger, he had probably no need to find out anything more about it; he simply applied his category, that is his conceptualization, and adopted the right course of action.

A point of view or an interest can lead to a conceptualization of a situation or incident, and the different interests of different people can result in different conceptualizations of the same situation. When Jay Wadsworth talked yesterday on orientation and mobility, he gave an instance when he had described a trainee with a cane as "making contact with" a truck at the edge of a sidewalk, but the client had used the term "collide with". In an argument, we have predispositions, of course, and others have biases; we are consistent and firm, others are rigid. Was Hamlet mad?, cunning?, confused?, homosexual?, oedipal?, or any combination of these? And is adolescence an age-group, a developmental stage, or a disease? One's situation and interest may dominate the position we take, or, more properly, that takes us, along a certain course of action.

Conceptualizations which lead to very different actions can be expressed even by different single words being applied to a common situation or thing. Several years ago, a missionary among Tibetan refugees in the north of India found her missionary zeal sorely tested when she was offered the inevitable drink of tea on her visits to Tibetan homes, because the tea had fat floating on the surface. But her increasing fear of giving physical evidence of her nausea vanished in an instant when a more experienced colleague said to her, "Don't think of it as tea, think of it as soup." Again, if people with "white" skins described themselves more accurately, as "pinkish", or "brownish-pink", racial prejudice would be more difficult to sustain. Political parties with names like "Pink Action" or "Keep Canada Pink" would be quite hard to take seriously. Similarly, parents who consult members of professions about their child would lose a good deal of their awe if they referred to them as specialists, not experts.

One reason why conceptualizing preoccupies us is historical. I worked for a year as a clinical psychologist in a rehabilitation setting for physically handicapped children. During that period I came across nine children who were blind or severely visually impaired as well as physically handicapped. I was struck first by the helplessness, observed and stated, of their parents, which seemed deeper than that of, for instance, parents with cerebral palsied or retarded children. I was even more struck by my own sense of inadequacy in trying to assess these children developmentally because I kept stumbling over my assumptions, as a sighted person who had learned about child development in books on sighted children. I was thinking only out of a sighted frame of reference, and indeed what else could be the case? I had been trained using ideas, procedures, instruments, clinical suggestions and theories which had been developed from an understanding of child development that took sightedness for granted.

Following this frustrating and challenging experience and to a large extent as a result of it, I joined with the other author (Joyce Nesker Simmons) and several others in a three year study which produced a handbook for parents of young blind children (1976). Despite our multidisciplinary group comprising professionals each with several years' experience with handicapped children, we all found it very difficult to pitch our expectations of young blind children in play settings at an appropriate level. As a result of finding ourselves repeatedly helpless and confused, we gradually came to notice that we were generally trying to understand the blind children by making comparisons with sighted children of

the same age, in terms of a knowledge base conceived in the same set of terms as for sighted children of the same age. Eventually we began to work out what assumptions about learning and development were in operation in traditional writing about early childhood development, and to discuss what the implications were of thinking outside those assumptions when some of them, especially to do with the role of the senses in gaining information, did not apply. And lastly we eventually realized that, once we had said that blind children lagged behind sighted children in certain aspects of development, we had not really said very much. Further, if we planned programmes, or advised parents, on the basis of identified differences, we were reinforcing the comparison with sighted children by helping the blind children to catch up with the latter, or by helping them to compensate for "deficits". Both strategies emphasized difference from a norm, and failed to view blind children on their own terms.

Reconceptualizing

Conceptualizing, making maps, creating conceptual models are simply means of imposing some sort of understandable order on some aspects of the world. We find descriptive conceptualizations more useful than explanatory ones, which can tend to take over and become closed systems. Conceptualizations are useful for showing the boundaries of one's knowledge, the gaps inside those boundaries, and the relationships among the elements of that knowledge. They are, in other words, devices to clarify what one believes to be the case, to make sense of something; they set the scene, and allow us both to stand back to look at it, and to shift the scenery about to correspond to what seems to us an appropriate arrangement.

It is still common to find people who think of children through only one explanation, one theoretical framework. We tend to avoid explanations that cover all children, but we do attempt to create conceptual descriptions that apply to all children, and leave ourselves and everyone else free to explain in specific, unique terms any individual child's behavior, described generically. The traditional way of conceptualizing blind children has been dominated by the comparison with sighted children; indeed it has been in terms of development worked out on sighted children. This simply fails to do justice, human and conceptual, to blind children, because the conceptualization which directs one's thinking and action is not derived from the children under scrutiny. The comparative mode may tell you what blind children are not, but it does not tell you what their developmental processes are like. It is always a view from the outside.

We are not denying that comparisons with blind children can make a contribution to our understanding of blind children, but we do object strongly to comparing blind children to sighted children and giving conceptual and clinical priority to the latter. Thus Gesell and Amatruda forty years ago talked about young blind children as sufficiently like sighted children developmentally for both groups to be educated in substantially the same way. That position is still propounded in the 1974 edition of their classic work, "Developmental Diagnosis". Norris, Spaulding and Brodie suggested thirty years ago that children blinded by retrolental fibroplasia could succeed more or less as well at school as sighted children, if they had experienced in early childhood a supportive nursery school and family environment. More cautious comparisons were made by Wills and Burlingham in Britain and Fraiberg in the United States, but Lairy's comment on Fraiberg is shrewd. She suggested that while books such as Fraiberg's "Insights from the Blind" could add to our understanding of the development of young blind children, the limitations of such an approach also became apparent.

To go forward in understanding the developmental route taken by young children as a result of blindness, we need much more than a comparative approach. The latter appears to have face validity, to be a common-sense approach. We cannot forget, however, Einstein's description of common sense as the deposit of prejudice laid down in the mind before the age of eighteen. What has to be done, in our estimate, is to take blind children and sighted children and compare them in the same terms, and as closely as possible on equal terms, terms not derived from the functioning of the larger group (too easily conceptualized as the 'normal' group) but from a generic perspective, encompassing both groups.

The research and clinical literature hardly addresses itself to the type of conceptual issue we have been propounding, with two major exceptions which we shall discuss shortly. Most of our early clues to reconceptualizing our thinking about how young blind children develop and what they need come from their parents. The parents who seemed to us to be raising a young blind child most successfully were those who basically gave their children a wide range of opportunities to explore, encouraged them to do so, and then explained whatever it was the children discovered. They were not in the business of developing general positions; instead, they were involved in the business of finding the most useful things to do and approaches to use in bringing up their children. Each parent was constantly looking for anything that helped to develop his/her own child, that worked for that child. Comparisons with sighted children in general, and especially with the

blind child's brothers or sisters, were typically seen as limited and limiting.

Two writers, as mentioned before, were very important to us in shaping our progressive reconceptualization of the development of young blind children. The first was Thomas Cutsforth, whose book of fifty years ago, "the Blind in School and Society", is well written, passionate and persuasive. He claimed, simply but powerfully, that the state of blindness totally transformed the perceptual and cognitive development of children.

> "No single mental activity of the congenitally blind child is not distorted by the absence of sight. Not a single sense escapes; the sensory equipment and processes of observing are organized quite differently in the blind from the normal seeing child. ..It is equally unjust and inefficient to proceed with a congenitally blind child as though he possessed the sensory and perceptual organization of a seeing child as to treat a child with visual appreciation of size, form, distance and color, as though he lacked this advantage." (Cutsforth, 1951, p.3-4).

David Warren, an academic developmental psychologist, has emphasized the heterogeneity of blind children and how that heterogeneity renders suspect traditional generalizations about blind children. Further, he suggests that the development of the visually impaired child occurs

> "..under a different set of circumstances than does that of the sighted child, and it may very well be that the optimal rate, or even sequence, of development with varying degrees of visual impairment is different from that of development with unimpaired vision. The developmental course of the sighted child would then be an inappropriate yardstick. An intervention program might not be effective, but even if it were effective in avoiding a lag, avoidance of the lag might not be consonant with the optimal developmental course for the visually impaired child. He would be led into a non-optimal course of development, simply for the goal of having him develop like a sighted child. (Warren, 1981, p. 198-199).

Both Cutsforth and Warren use comparisons, but in order to point out its limits, to identify areas where one has to think again. Neither accepts the position that thinking about blind children can proceed simply by seeing where they differ from sighted children, by giving the latter normative, and by

implication, preferred developmental status. We are not arguing that blindness is not a handicap. We are, however, arguing that comparison by difference/deficit is a dead end, and that the use of reconceptualization frees one to think about, and plan for, young blind children in terms that take account of their unique developmental mode.

Hence, instead of the question, "What is the difference between young blind and sighted children?" we ask, "Given a child who has hearing, touch, smell and taste, what way of interacting with and learning about the world is entailed, what particular route is laid down, and therefore what approaches are required to facilitate the development of the child so endowed?" We start with the position (hardly original) that information comes from the senses, that we form representations of what we experience senorily and thus make sense of our world. In crude, possibly unacceptable, language, the contents of the mind come from the senses. A young blind child and a young sighted child both fit into this position. There are examples of people with different numbers and different combinations of senses. Some people have three (deaf-blind) and some have four (blind), though obviously most have five, but by thinking about each combination as a separate cluster, a unique sensory system, one specialized way of gathering information and interpreting it, one conceptualizes people in terms of their specific form of development. The phrase we use to accommodate different forms of development based on different sensory provison, is alternative normalities. Again, it does not matter for our purposes that 99% of people fall into the five-sensed category, that there is one particular sensory normality for the vast majority of people. Conceptually speaking, several kinds of sensory systems exist and we argue that understanding of development, needs and provison for each of these systems proceeds best by treating each group as having a particular developmental normality, following a particular developmental route.

Concluding Statement

In case it has not been obvious, we are not claiming that we have a novel position. Instead, we are trying to find ways of enabling anyone connected with young blind children to make explicit his/her conceptualization of them, and then to reconceptualize the development of these children in terms of their unique sensory equipment and its perceptual and cognitive implications. We see our approach as practical, because conceptual, providing a device for systematizing one's information and hunches and for examining one's assumptions. To use biological analogy, we are asking people to listen to their own breathing.

REFERENCES

Allport, Gordon W. The Nature of Prejudice. Garden City, New York: Doubleday and Co. Inc. (Anchor Books edition), 1958.

Burlingham, D. Some problems of ego development in blind children. Psychoanalytic Study of the Child, 1965, 20, 194-208.

Cutforth, Thomas U. The Blind in School and Society (new ed.). New York: American Foundation for the Blind, 1951.

Davidson, I., Fletcher, J., Howard, M., Joeck, I., Santin, S., Nesker Simmons, J., Weaver, D. Handbook for Parents of Preschool Blind Children. Toronto: Ministry of Education, Ontario, 1976.

Davidson, Iain F.W.K. and Nesker Simmons, Joyce. Mediating the environment for young blind children: a conceptualization. Journal of Visual Impairment and Blindness, 78, 6, 251-255, 1984.

Fraiberg, S. Insights from the Blind. New York: Basic Books Inc., 1977.

Gesell, A. and Amatruda, C.S. Developmental Diagnosis: Normal and Abnormal Child Development. (3rd ed.), edited by Knobloch, H. and Pasamanick, B. New York: Harper and Row, Publishers, 1974.

Lairy, G. Review of Insights from the Blind. Journal of Visual Impairment and Blindness, 1978, 72, 154-155.

Nesker Simmons, Joyce and Davidson, Iain F.W.K. Mediation for young blind children: An introduction to the literature. Journal of Visual Impairment and Blindness, 78, 3, 118-120, 1984.

Norris, M., Spaulding, P.J., Brodie, F.H. Blindness in Children. Chicago: Chicago University Press, 1957.

Warren, David. Visual impairments. In, J.M. Kaufman and D.P. Hallahan (eds). Handbook of Special Education. Englewood Cliffs, N.J.: Prentice Hall, 1981.

Wills, D. Some observations on blind nursery school children's understanding of their world. Psychoanalytic Study of the Child, 1965, 20, 344-364.

A COMPREHENSIVE SCHOOL BASED PHYSICAL EDUCATION PROGRAM FOR THE VISUALLY IMPAIRED CHILD

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A NO-HOLDS-BARRED approach to leisure programming for the visually impaired child is a process of breaking down barriers and demonstrating that a comprehensive physical education program can be accomplished through the school system. Outdoor pursuit activities can be substituted for class credit when it is impossible for the child to be involved in the regular program, thereby allowing the student to participate in, and achieve credit for, physical education classes up to and including grade 12.

There is much written about the adaptation of physical education for the visually impaired child in school. There is less written about adapting outdoor pursuit activities because they have only more recently been accepted as a possible alternative. It seems that we could sit and discuss theories until we are blue in the face, but there comes a time when we want more; we want solutions to the problem of implementing programs. In this paper I hope to stay away from theories per se, not because theories are unimportant, (on the contrary), but because theories are the tools by which we should do our work and they are not the answers on which we should rest. The time has come when we should discuss putting theories into practical use.

There are three items on my agenda. The first is to discuss terms and concepts that are important in implementing comprehensive physical education programs so that we can develop a common base of understanding. The second is to look at my program the way it is operating now (as a result of the philosophy I have outlined), the barriers that had to be broken down and how it operates in the Calgary Catholic School Board system. The third item is to look at what a concerned individual can be doing to improve programs or to implement a comprehensive physical education program.

CONCEPTS AND TERMS

To begin, I would like to discuss terms and concepts that are important when working with young people in this type of program. By doing this we will be able to share a common base of understanding.

Buckminster Fuller brings to our attention a word seldom used and even more seldom understood. This word is SYNERGY. It is a hard word to get a feel for, and yet we live with its consequences everyday of our lives. Buckminster Fuller defines synergy as "behavior of whole systems unpredicted by the separately observed behaviors of any of the system's separate parts or any subassembly of the system's parts." (Fuller, 1969, p. 71) I can almost see the questioning look on your faces. Well, fortunately Buckminster Fuller goes on to help us understand this concept. If we were to look at steel, we would see a product whose tensile strength is 50% stronger than the sum of its component, alloy tensile strengths. We see this concept "synergy" at work in nature, in chemistry and in programs. It is important then, to think not in terms of single components, or in terms of adding component parts, but in terms of a result that will be much greater than the sum of the component parts. In effect what will happen when you apply the concept of synergy to a program is that you will create something greater and more powerful than you could ever imagine.

Another concept that is essential to our base of understanding is that even as carpenters build with the tools of their trade, we too are builders. WE ARE, in effect, THE BUILDERS OF SELF-ESTEEM, SELF-CONFIDENCE AND SELF-WORTH. I believe we are trying to build children up, not tear them down. The first tool we need to tangibly demonstrate is care, because children who believe that they are cared for seldom pose a serious behavioral problem. They care in return. They care for others around them and for you.

Secondly, RESPONSIBILITY is among the many things we hope to build within the child. Kids are people too! They like to be given as much responsibility as they can handle, but they need help to accept their new found responsibilities. We can help in many ways. For example, we can avoid performing tasks that the child can do for himself. This trap is often fallen into when we have standards or expectations that children are incapable of meeting. The second tool we must use in building self esteem then is to have HIGH, BUT REALISTIC EXPECTATIONS of the child and to make sure that THE PRODUCT IS NOT AS IMPORTANT AS THE CHILD'S EFFORT.

It is an amazing quirk in nature that allows us as adults to use tools that will improve the effort of the child. Two more valuable tools we have, are the ability to ASK and the ability NOT to DEMAND. Demanding usually decreases the child's desire to perform the task. When we ask it helps the child's desire to perform the task. This desire helps him to feel okay not only about what he is doing but also about himself. Asking and not demanding is a way we have of helping the child increase his self-esteem.

Another tool for building up the child is to give POSITIVE FEEDBACK and REINFORCEMENT. The key here is to build within the child A REPERTOIRE OR SUCCESS EXPERIENCES and give him COPING STRATEGIES TO HANDLE his FAILURES.

Positive feedback and reinforcement, (although we sometimes forget to do it), should be obvious and self-explanatory. What is not obvious is how to help the child develop a repetoire of success experiences or even why we should want to do this. I believe we are what we are in life because of the EXPERIENCES we have. Or as Dewey put it, "Everything depends on the quality of the experience which is had" (Park, 1952, p. 108). "We learn any particular item in the degree that we accept it in our hearts for use in life... We learn any particular item in the degree that it has meaning to us" (Park, 1952, p. 139).

A repertoire of success experiences is necessary because no one likes to repeat failures. This is rather obvious. How many experiences would you want to repeat if you could not keep up with others, were not enjoying yourself and were failing (even if only in your mind)? The answer ... not many. So let us create another scenario. In this situation you are allowed to progress one step at a time, building success experiences, working near your limit so that you were challenged, and having fun. This is a quality experience which promotes the desire within the child to have further experiences. This is the concept of CHILD SPECIFIC APPROPRIATE PROGRESSION. Just think of the devastating effect on a child if we ask him to run a marathon before we teach him to jog properly. This is, in effect, what we are doing if we place a child into a grade 10 physical education class if he has not participated for the past four years. Children are very perceptive, they know when they look out of place; therefore, integrating them into a physical education class before they have gone through the correct progression, can do more harm than good. With EXTRA PRACTICE and the PATIENCE of skilled professionals in the school system, integration need not be deleterious.

Children are proud and afraid. Once you initiate them into a new program they have to start taking risks and then fear becomes one of the hardest components to help them overcome. Visually impaired children have the need to live a full life and take risks like other children do. They have the need to fall off of their bicycles and get hurt.

There are many different components to risk taking. If we view risk as a spectrum then we have, for example, meeting people and making friends on the one end and climbing Mount Everest and endangering one's life on the other. Both can be threatening to those who are placed in the respective situation. Both involve risk-taking. And as Bascaglia states, "I really believe most people are afraid of life... We are afraid of life, therefore we don't experience, we don't see. We don't feel. We don't risk! We don't care! And therefore we don't live -- because life means being actively involved. Life means getting your hands dirty. Life means falling flat on your face. Life means going beyond yourself -- into the stars." (Bascaglia, 1982, p. 168 - 169).

In my programs I give the children a chance to get their hands dirty; a chance to experience life and all of the wonderful adventures that it has to offer. I maintain only the highest levels of safety, but the children are not protected from SUBJECTIVE DANGERS. These are the dangers which lie in their minds and these dangers are the same for the sighted as well as for the visually impaired. An example of this would be when you are mountain climbing. You are following the leader and are securely belayed (which means that if you fell you would fall no further than the stretch of the rope), there is no danger of falling, and yet you are too afraid to make the move. The dangers lie completely in your mind and these fears of taking a risk are the hardest to overcome.

The truest of all dangers lie in the state of mind of the individual. A handicap lies in the reaches of our mind, not in the condition of our sight. What we believe is generally the way we behave. If the teacher has an ENTHUSIASTIC and POSITIVE manner then a visually impaired student can do almost any activity with the correct progression. There are, of course, activities that are very difficult for the visually impaired student to do but adaptations or substitutions are easily made. With continued success experiences the student knows that he can do many activities, and soon believes that he is entitled to THE SAME RIGHTS FOR PHYSICAL EDUCATION AND RECREATION as his sighted counterpart. When this happens there is no longer a handicap!

THE PROGRAM

For me, it is a synergistic approach, which uses the tools and concepts discussed above. It is a program based on care, responsibility, successful experiences through appropriate progression, patience, and risk taking. It is a program which operates effectively within the school system.

My employer had the foresight to realize that this was not (nor ever could be) a regular job. Academic time is too important to visually impaired students to pull them out of school to give them the additional skill, practice and experiences required for their credits and for their integration into physical education classes. As a result flex-time was arranged so that I could do my work without being hindered under the constraints of regular school hours. The result is that programs for fun as well as for credit take place week nights and every second weekend. Weekend activities are on volunteer time because there are such a large number of lifetime leisure activities which can not be accommodated after school hours and before a reasonable bedtime.

Activities change every semester and every year depending on the needs of the students. The program is growing quickly with more students being accommodated and more activities being implemented. Because of all the students who required the service and because there was only me, it was very difficult in the beginning. At that time students were "being put in a closet" during physical education class. Teachers, parents, and administrators were sceptical that such a program could operate effectively and safely. There were many people who needed convincing about the merits of such a program. Now, with increased parent involvement, a core of highly skilled volunteers and more enthusiastic administrative support, it is easier to facilitate child specific programs.

I think in terms of adventures, not merely of activities or individual programs. They then become experiences that young people will always remember. To me it is quality that is important in a program and not the number of young people involved or the number of activities provided. But I have one rule ... we will try everything and we will make dreams happen. For us there are no roadblocks or barriers. The students dream with me and know that one day we will be cycling around Europe, sea kayaking on the GULF ISLANDS, climbing a mountain peak higher than 14,000 feet, or helicopter backpacking into some remote wilderness area. My students also know that they will learn lifetime leisure skills while they are being challenged, having fun, and

obtaining credits for physical education until they graduate.

The following list is not complete and may not happen every year, but will give you an idea of some of the activities we have done over the last two years. ACTIVITIES: video games night, bicycling and bicycle touring, swimming, rock climbing, cross-country skiing, winter camping, summer camping, youth hostel touring, downhill skiing, helicopter backpacking, hiking in the mountains, go-karts, all terrain cycles, fitness (weight lifting and running), canoeing, kayaking, rafting, horseback riding, ice climbing, sailing, waterskiing, adventure ropes course, wind surfing, track and field, goalball, archery, target shooting, ice skating, play ground skills, and yoga.

When a student is able to participate in the regular program I am there as a source of information to teachers on possible strategies for adaptation or to assist in the class on a one-to-one basis when required. When a student cannot participate in the regular physical education program, the above activities are substituted instead. If groups are required for an activity then I invite other students to participate for fun. This works very well and I have no difficulty filling an activity to maximum capacity. This has the effect of a run-away train and dreams unfold in the excitement of the moment. The next activity is full before I get it off the drawing board.

What would life be like without dreams of adventure and without people to share those dreams with?

CONCLUSIONS

One must believe very strongly in the necessity of equal opportunities in physical education, in life-time leisure skills, and in outdoor pursuits in order to make it happen. I do believe in these ideas and strive to keep them as a component of the program. I no longer dream alone; the visually impaired children in the Calgary Catholic Schools are advocates of their own dreams. Since I started I have noticed remarkable progression in my students. I am not alone in noticing a courage and determination in these children to express their own needs for growth, needs that were dormant and unfulfilled for so long.

Why did their needs lie dormant? Why are the needs of children put "on the back burner"? I feel the answer lies in the fact that large organizations cause people to have feelings of anxiety and insecurity. The consequence is to avoid change and play it safe. The resulting condition is

that too many people see too many road blocks and barriers. This is the short sightedness of a few. In this program I do not believe that there are any road blocks or any barriers to creating a program of which the children can be proud.

Believe that you too can affect the quality of your life as well as the lives of others. For instance, start a club where people with like interests can be drawn together. The club gives your group an identity and a purpose. Use your talents to their optimum. If you do not have the skills to teach the activities, become a facilitator. Start slowly with a reasonable progression, but make it happen and with quality.

The keys to operating a comprehensive school-based physical education program are:

1. Think synergistically
2. Use child specific progression
3. Maintain flexible working hours
4. Be builders of self-confidence, self-esteem and self-worth
5. Give students the responsibility they deserve
6. Maintain high but realistic expectations
7. Help the children to overcome fear and take risks. It is most important to believe in yourself, to believe your students and to believe in your program.

REFERENCES

(1) Bascaglia, L.: Loving, Living and Learning. New York, Fawcett Columbine, 1982.

(2) Fuller, R.B.: Operating Manual for Spaceship Earth. New York, Simon and Schuster, 1969.

(3) Park, J.: Selected Readings in the Philosophy of Education. New York, The MacMillan Company, 1958.

CAREER AWARENESS AND PREPARATION: A GROUP EFFORT

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Career awareness and preparation have often been lumped together under the term career education, and treated as a single course in High School. In fact, career development is a lifelong process. It may include paid or unpaid work, it is productive in nature, and requires some independence and maturity on the part of the worker.

For the visually handicapped child, career development involves many people who form a network of support, instruction, and direction. The parents, volunteers, and professionals must work together as an open group where they share information, expertise, and responsibility to ensure that a visually handicapped student is prepared for a beginning career.

Career awareness involves a realistic understanding of oneself in relation to the world of work. Self awareness includes one's interests, temperaments, aptitudes and values, all of which combine to build a positive self identity. Career awareness includes basic education in reading, writing and math, as well as science, social studies and other elementary subjects. It involves an awareness of a variety of careers and the skills required to be successful in a career. It involves an awareness of the economic benefits of work.

Career preparation includes an application of these educational skills and aptitudes. It involves the practice and the use of social and communication skills in order to secure and hold a beginning job. The ability to make rational, intelligent choices concerning an entry position into employment or into further education is one of the main aims of early career development.

One other critical aspect in career development for the visually handicapped is that blind or visually impaired persons may have to be better at whatever they do to convince many people today that they can handle a job. When asked about the reasons for their succers, successfully employed blind people have indicated that in their experience better than average training was necessary. (Kenmore, Davidson, 1981).

How do we ensure this better training, decision making ability, career preparation, and awareness of self? It is a long term developmental sequence and will require the concentrated efforts of many people. This group of people includes parents, doctors, preschool workers, ophthalmologists, optometrists, teachers, aides, counsellors, principals, volunteer groups, rehabilitation workers, ultimately employers and the business community, and of course the visually impaired person. It is a large and diverse group that rarely if ever meets together at one time but the accumulated knowledge and experience must be communicated and made available to all. Each individual, parent, volunteer or professional has special insights, expertise, and personal knowledge which enhances the career development of a visually handicapped youngster. However, with such a diverse group that spans a long period of time, there is a danger of assuming that "the other person" is looking after or is responsible for the basic needs of the visually handicapped person.

What are these basic needs? A recent evaluation of visually handicapped clients entering a rehabilitation program indicated some characteristics which would contribute to successful employment or future vocational training. These basic factors in order of importance were:

1. Home management skills.
2. Previous employment experience.
3. Age (above thirty years old).
4. High school education or better.
5. High level of career maturity (Springfield, Van Der Kolk, 1984).

All of these aspects are components for successful career development, but surely we, as a group, can attain most of these goals in less than thirty years. All of these factors can and should be introduced if not fully achieved in the earlier stages of career development.

This group effort by people working toward independence and career maturity must include the education of those well meaning persons who themselves have not yet come to terms with visual impairment, and who are over protective or misguided in their approach to supporting a visually handicapped person's growth and independence. An individual who is visually handicapped, yet has good self identity and awareness and can demonstrate relative independence and abilities in the home and workplace, will ultimately educate employers and the public at large.

The lifelong process begins at home with the parents. They must come to terms with the fact that their child is or has become visually impaired. They are the first to address this special circumstance of their child and to take action in ensuring as normal development as possible for their child. But parents need help and are assisted initially by doctors, ophthalmologists and other medical personnel. This initial core group expands to include preschool workers and other child care professionals who may assist in training parents to implement early intervention programs that allow a visually impaired child to develop early independence and social behaviors.

During early childhood, parent support groups offer moral support and practical suggestions to help parents achieve goals and to recognize successes in severely multihandicapped children. Help and guidance of the group, parents efforts in early stimulation and establishing independent activities are most important. Independent personal hygiene and eating skills, good grooming, and appropriate dressing techniques need to be taught in early childhood.

Parents can begin elementary prevocational activities by assigning small tasks and supervising regular responsibilities appropriate to the age of the child. Cooking, baking, small cleaning and maintenance jobs or hobbies earn the child satisfaction or praise for a job well done. The beginnings of responsibility and independence are nurtured; natural skills and abilities are noticed and encouraged by the parents.

Obviously sensitive, supporting parents quickly become vital to the co-operation, planning and direction of a group effort aimed at individual career development for their youngster. Their realism and input based upon first hand knowledge of their child is most important in guiding other group members. But the degree of parental expectations is set early. Doctors, ophthamologists and specialists play a crucial role in advising and supporting parents upon recognition of a severe visual impairment. Since visual impairment is a low incidence handicap many general practitioners may be unfamiliar with available specialized services. The medical community and support agencies such as the CNIB have a responsibility to ensure that their services and clinics are advertised regularly.

Doctors remain as consulting members of the group throughout career development. Over the long term, families call upon medical specialists for prescriptions of aids, referral for specialized services, and possibly recommendations for educational placement.

An important indicator of career maturity is the ability of a visually handicapped person to explain his or her visual handicap in medical and functional terms to a potential employer. (Dickson, 1982). Ophthamologists and optometrists are the most qualified to explain particular visual conditions in terms that students can relate to and understand.

When a child reaches school age, the group of parents, medical, technical, and social workers gains some new members. Teachers, aides, principals, and other school personnel become actively involved in the career development process. School programs for multihandicapped children build upon self help and independence achieved to date, depending on the ability level and development of the child. Self awareness activities continue in the social context of a peer group in the more formal school setting. Elementary activities such as sharing and discussion of personal differences, including those of the visually impaired child in the group can benefit all the children by fostering understanding, co-operation, and acceptance of individual differences. These elementary school activities allow all youngsters, including visually impaired, an opportunity to begin to develop a realistic understanding of others. Opportunities for groups to explore likes and dislikes, abilities, and work values, lead to successful performance with peers and a commitment to school.

In later stages of elementary career education, career awareness activities can begin with a discussion of parents or neighbours roles, class visitors and speakers from the community. Visitors should include handicapped adults who can discuss with the class, work related experience and training. Field visits to work sites of class visitors is a valuable follow up activity.

At the Junior High level, the group of professionals supporting career development shifts once again. Career development activities broaden to include more diversified or specialized subjects such as economics, industrial education, home economics, typing, etc. New materials, methods, and demands are placed on a visually handicapped student. Work habits, attitudes, individual strengths and weaknesses that have been established are refined and tested in new class and group situations. More emphasis on adaptive aids to accomplish specialized tasks may require the input of low vision specialists and rehabilitation personnel.

Responsibilities for the student increase; children are working towards independence, skills for personal hygiene, clothing care and mobility. Further goals of independent living such as meal planning, budgeting, banking, and shopping require the input and planning effort of parents, teachers and students. Too often these basic skills are overlooked because one group member assumes the others are covering them.

Peer discussion, pressures, attitudes and opinions become important at this stage as future career goals and decisions loom closer.

A good magazine for discussion about career information and topics of interest to this age group is Life Prints (Blind Skills Inc., 1981), a recorded Braille large print magazine specifically for visually handicapped youth. Regular departments on careers, adaptive aids, sports and recreation, books and agency information address many of the elements of career development, in a format that is interesting and accessible for students.

At the High School level, career education or exploration has traditionally begun. If elementary self awareness and career awareness has been overlooked there is a gap to fill before career exploration or preparation can begin.

Vocational counsellors, and school guidance counsellors become important group members co-ordinating the efforts of career preparation. Often counsellors are intimately involved in school programming and community liaison activities. However, they may not be familiar with the specific needs and concerns of the visually handicapped. For those counsellors with no previous experience with visually handicapped people there is a possibility that sympathy or pity could impede effective counselling about career decisions that a student needs to make. Many counsellors fear that they are unable to deal effectively with disabled students in an integrated school setting, hence they spend their time on current academic needs rather than future career goals. (Roberts 1983, Jones, Koestler Ed.) Guidance counsellors in public schools need support in recognizing that visually impaired persons are capable of a wide range of careers and not simply stereotyped ones. This information can be partially supplied by role models of successfully employed visually impaired persons. Yet counsellors must be aware that there is no fixed list of jobs that are performed by the visually impaired. Counsellors need to understand the nature of the visual handicap a student may have, but emphasis must be placed on abilities, not disabilities. School and vocational guidance personnel need the informed opinion of all group members - family, medical, volunteers, and professionals.

There is a tendancy for those who give career advice to overestimate the capabilities of visually handicapped young people. (Chapman, 1978, Davidson 1981). It has been suggested "The type of work they would undertake if they were not visually handicapped is perhaps the best measure of the appropriateness of the work in which they actually engage".

The counsellor has a crucial role in exploring the options with a visually impaired student. Examining the education options and career implications, leading the student through a self analysis of strengths, expectations, limitations - helping to set realistic goals, and clarifying perceptions of self as related to the world of work, are all of paramount importance. The school counsellor has a co-ordinating role to play within the group that has been building awareness and career maturity to date.

Other knowledgeable persons in the group who know the visually handicapped student will assist in this advice and consultation. A thorough assessment plus communication amongst the group, counsellor, and student will ultimately lead to the student making his own decisions regarding career options.

Parents, doctors, career counsellors, volunteers may possibly all contribute suggestions when asked by the student as to the best strategy to enter a particular job or field. Vocational instructors, teachers, counsellors and guidance counsellors need to direct the student to information about occupational requirements, benefits, training, and future outlook for occupational groups. Studying the skills, temperments and worker characteristics are all career awareness activities that help the student to narrow the options and choices.

One proven method of gaining self awareness, testing one's abilities and gaining valuable experience is through short term work placement. Work experience opportunities from family jobs, to in-school jobs, or after school and summer jobs are invaluable opportunities to learn about the world of work. Paid or unpaid, sheltered employment, working for a community group or agency, all of these experiences are equally valuable to a student, depending on his ability level and career maturity.

Work experience tests the many educational and personal/social skills acquired to date; it requires independence, mobility, and maturity. Job seeking skills used in applying for a position, the interview, and follow up, are tested in a real life sense and not simply in a role play classroom situation. The competitiveness of the work

place, employer's demands and evaluation of performance as a worker are motivating situations for students. Often they are pleasantly surprised by praise, sometimes they are faced with failure and need to refine or improve certain skills.

Summer work experience programs for blind and visually impaired students integrated in public schools have reported good results. (Cacich, 1983). It has been shown that many elements of self and career awareness can be explored in a relatively short summer period and be of benefit to all participants. A project (Seeds) sponsored by CNIB Maritime Division gave an opportunity for students to compete, apply for a limited number of positions and gain valuable work experience.

The benefits of such programs include focusing future career goals, making employment connections and heightening community and employer awareness of the capabilities of blind and visually impaired workers. The meaning of phrases like: "The need to be over prepared for the job" or "Better than average training is required for success" take on new importance.

The placement of students into a work setting requires the cumulative efforts, of parents, teachers, vocational instructors, mobility instructors, rehabilitation workers, medical personnel, placement specialists, administrators - the list of group members goes on. The support network and follow up after a placement is necessary to remediate deficiencies and plan new initiatives. Group efforts have become successful when the young visually handicapped person plays a major role in making rational and intelligent career decisions. Good choices, based on a knowledge of self and a realistic awareness of opportunities indicate individual career maturity.

Throughout this discussion I have emphasized the developmental nature of career awareness and the fact that there are many contributors to this process. The support network is vast, the membership of the group or network shifts constantly as environments change and the career development proceeds. Communication amongst such a large and diverse group is important but difficult to achieve. Individuals who have been part of interdisciplinary teams know of the advantages but also the problems in the team process.

The members of a group supporting career development must adopt a transdisciplinary group approach. A transdisciplinary joint team approach assumes the group performs services together. Group members must be willing to share expertise and to educate other members as necessary.

The ideal group encourages open communication among its members, and shares leadership and decision-making responsibilities. It is important for all group members to recognize that one individual or discipline cannot consider and implement all the elements of career development.

Individual personalities, professional rivalry or domination must not be allowed to interfere with the career developmental process. Although parents sometimes see their child with a halo, we must recognize that, "parents and paraprofessionals have more direct contact with a child than any other team members - their contributions should be solicited and valued as much as any other team member's perspective". (Baily, 1984). The task of career development for visually handicapped young people is an important one which demands the efforts and cooperation of many to be successful.

BIBLIOGRAPHY

Baily, D.B. - A triaxial model of the interdisciplinary team and group process Exceptional Children, Sept. 1984.

CCM, Editor - LIFEPRINTS Magazine Blindskills, Inc., Salem Oregon, 1983.

Cacich, J. and Dosch, T.G., - Summer work experience program for the visually handicapped, Journal of Visual Impairment and Blindness, Nov. 1983.

Cobb, R.B. - A curriculum based approach to vocational assessment, Teaching Exceptional Children. Summer 1983.

Cocker, G.C. Ed. - Special issue on career education Education of the Visually Handicapped, Winter 1983.

Courinston, M. et al - The measurement of attitudes towards blindness and its importance for rehabilitation International Journal of Rehabilitation Research, March 1983.

Davidson, T. - Things are getting better all the time? Mainstreaming, integration, and vocational Development for the 1980's. Blindness, AAWB Annual 1980-81.

Dickson, M.B. - P.K. Career Club for blind job seekers. Journal of Visual Impairment and Blindness. Jan. 1982.

Ellington, Carol, Winicoff, Leslie - An Introduction to Career Education at the Elementary Level: With Parent School and Community Involvement. Paper presented at International Convention of Council for Exceptional Children, Houston, TX, 1982.

Field, Sharon L. - Career Education: The link between high school and independent living Journal of Career Education, June 1982.

Graves, W.H. - Career development theory applies to the delivery of services to blind and visually impaired persons. Yearbook of the Association for Education and Rehabilitation of the Blind and Visually Impaired 1983.

Green, D. and Wing, J. - Tapping Community Resources, Reston, VA 1980. Council for Exceptional Children.

Harrington, T.F. - Handbook of Career Planning for Special Needs Students. Rockville, Maryland Aspen Publications 1982.

Hursh, N.C. et al - A Career Education Model for students with special needs. Teaching Exceptional Children September 1982.

Jones, Rev. R. and Koestler, F.A. - Breaking traditions education and career opportunities for blind and visually impaired women. Journal of Visual Impairment and Blindness June 1983.

Jones, William C. - Preparing blind persons for community work experience Vocational Evaluation and Work Adjustment Bulletin Sept. 1976.

Luxton, K. - A jigsaw puzzle. Constructing a sound bridge to adulthood for visually handicapped adolescents. Blindness, AAWB Annual 1980-81.

Makowski, T.F. - Slice of Life Journal of Career Education June 1982.

Minugh, J. and Morse, D. - Parents, Counsellors, Career Planning and Vocational Programming for Handicapped Youth Ohio State University Columbus National Centre for Research in Vocational Education October 1981.

Murphy, L.C. and Banta, T.W. - Career education for the handicapped a model of cooperative programming for effective mainstreaming Journal of Career Education March 1981.

Pfouts, J.H. and Nixon, D.G. - The reality of the dream: present status of a sample of 98 totally blind adults Journal of Visual Impairment and Blindness Feb. 1982.

Ritlbauer, D.C. - Impacts of mainstreaming on career planning. Blindness, AAWB Annual 1980-81.

Shaw, R. - The role of industrial arts teachers in the vocational guidance of handicapped students Man/Society/Technology 41 vol. Feb. 1982.

Springfield, W. and Vander Kolk, C. - The Use of Assessment and Demographic Data for Program Planning and Prediction of Client Success Paper AAWB/AGIH Alliance Conference Nashville, Tennesse, June 1984.

Spungin, S.J. Ex. D. - Career development - the educational content. Yearbook of the Association for Education and Rehabilitation of the Blind and Visually Impaired 1983.

I CAN DO IT WITH EXPOSURE, EXPERIENCE, EXPECTATION AND ENJOYMENT!

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Through my career I have had the joy of interacting with, and being on the teams of hundreds of legally blind infants and children. They have been my teachers and have given me intense respect for human potential. They have also sent me on an on-going quest for key factors that contribute to the foundation for success and the belief that "I CAN DO IT," when the impact of blindness can interfere with acquisition of that potential.

There have been times, for example, that I have come home after working with a blind child that I know can do it, yet I have found myself asking such questions as:

-Why am I worried?

-What am I missing? (...is the child missing? ...are others missing?)

-Why is there frustration? (Mine..the child's..the parents...other professionals?)

-What needs to be done? (By me..the child..others?)

-What IS being done that is interfering? (By me..the child..others?)

-What statement is being made by the actions/non-action of the child?

-What is necessary for this child's success in this situation?

Obviously there is no checklist to resort to for specific answers to these questions. They remain with each child. However, as I try to understand the impact of blindness on learning and applying information, I am starting to recognize some patterns.

At this point, it is fair to state that as a Home Counsellor with Variety Club Blind Babies Foundation, my experiential education is heavily child-based. I am aware that the significance of this is reflected in an obvious bias and intensity with which I emphasize understanding the total dynamics affecting the unique perspective of learning and doing without vision, the primary integrating sense. However, most of the children that I work with, and who have taught ME, have little or no visual memory on which to build a foundation. In addition, they do not have the advantage of the incidental learning that their sighted peers do, and are initially totally dependent upon others for guidance, input and motivation to promote comprehension through use of their other modalities. Thus, the impact of severe visual impairment for this population is dramatic.

In trying to understand the components of the foundation for success that may be affected by blindness, I have become aware of the fact that the areas of EXPOSURE, EXPERIENCE and EXPECTATIONS play a primary role. Each is significant in isolation, but the synergistic combination of the three is almost essential for successful acquisition and application of the tools with the attitude of I CAN DO IT! In addition, if the element of ENJOYMENT is an intrinsic part of the overall picture, the opportunity for achievement will be enhanced! The challenge is to make realistic assessments of the total dynamics and determine if any of these areas needs to have more direct (active) and comprehensive introduction or reinforcement from the child's perspective. The variations within the esoteric situations of each child makes prescribed solutions to problems impossible, but a general awareness of some of the influences in the areas may help:

<u>EXPOSURE:</u>

In order for the blind infant to begin to recognize patterns of actions, events, and things happening around him...so that anticipation can lead to participation...he must have "hands on" sequential exposure. Without vision to confirm the existance of a world "out there," this infant is at-risk of staying in his own world. Therefore, early intervention will often consist of "co-acted" activities designed to establish bonding; to promote the child's awareness of self; and to establish object permanence and "moving out". It is natural

for these activities and the related verbal input to be child-centered and related to the immediate environment to establish an associative foundation.

While these interventions promote the care-givers' awareness of how to help their child become "part of the action," they also reinforce fears of what their blind child cannot yet understand and do. This can sometimes effect the overall pattern of exposure. For example, family shopping may be done when the child can be kept at home because "after all, there is nothing for him to see to keep him occupied." Instead of protecting the child from boredom, this attitude is actually depriving the child of the opportunity to share the noises, smells, action, people, sensations and sequences of going shopping (from getting into the car, going into the store, and bringing home specific items, etc. How does the food get there? The Good Fairy?) True, the associations will be fragmented and distorted until the context of the experience can be understood. However, the shared activity will help to promote curiosity and acceptnce of new situations. As these activities become common, it may also prevent the child from wanting to seek the security of home. Many visually-impaired children resist even simple transition because they cling to the comfort of familiarity.

Recently, I went to the store with a blind 2-year old. We were having the productive fun of putting things in the cart, shaking boxes, smelling fruits, and squeezing packages. However, when we were near the meat section, the butcher suddenly turned on the saw to cut meat. The resultant noise frightened the child, putting a halt to our activities. The initial response of the mother was to have the butcher stop until we were out of the store and to take the child home where we could continue exploring foods, but in a "safe" place. Obviously, at this stage checking out the saw would not help the child to "understand" what made the noise. However, with reassurance we remained in the store and gradually moved near the area of sound, making casual reference when the saw was going. The child picked up our calm acceptance, was gradually able to erase his fear, and in a short period of time, was saying "saw" when he heard the buzz. It had become "all right".

Exposure promotes awareness of existence of things and cause/effect. It stimulates curiosity and the asking of questions. It activates the imagination. It feeds the mind with information and can be varied or consistent; random or sequenced; tangible or undefined. It is not necessarily determined by what the child will "readily understand," but rather by what is happening.

Though the benefit of exposure is not dependent upon a foundation of association, it contributes to the whole. If, for example, the class is studying various kinds of trucks, has the child at least had enough exposure to fit together parts of the conversation? The concept of "truckness" will not come by sitting only in the cab of Dad's pickup. Has the child explored the inside of a mail truck, or perceived the vastness of a moving van, or felt the big wheels of a logging truck? It takes lots of exposure for the "4-C's" to take place. (COMPARE, CATEGORIZE, COMPREHEND and COMMUNICATE.)

There is reason that the ability to generalize is delayed in blind children. They do not have the instant confirmation, internalization and associated extension that vision provides. It takes more direct time and varied "hands-on" opportunity to assimilate, interpret and reinforce information. I am reminded of a blind boy who "finally" became toilet trained. In church, before the sermon was over, he anxiously pleaded with his mother to take him home. When they got outside where they could talk, his mother wanted to know what the urgency was. The child replied that he had to go to the bathroom. The mother pointed out that there was a bathroom in the church, and the child was both surprised and delighted (and probably relieved.) When he had been in diapers, there was no need to think of him missing out on that information, while yet sighted children might pick it up on their own. And, had the boy been exposed to the bathroom before he "was ready" to use the facilities, he would still have had the information in store for when it would be applicable. As it was, the result of this occurrence introduced the child to the joy of discovering that there were all sorts of bathrooms in all sorts of locations. In addition, the parents were reminded that there were lots of other things in the church and other "familiar" places that the siblings had taken in visually and that the boy was unaware of because they had kept him with them, rather than encouraging and helping him to explore the environment. In effect, they learned not to wait until the child gave clues of readiness to apply the information (those clues may never come,) but rather to expose because things are just there.

EXPERIENCE:

Exposure is a vital component of experience, but it alone will not necessarily result in understanding and application of information. In order for the child to have a REAL experiential foundation, he must have personal understanding of something in a way that will give him realistic associations. He needs to be able to process and interpret for meaning. Experience provides the tools for comprehensibly tying together.

We must be especially careful not to hurry the process of learning, which goes from concrete, to manipulative, to abstract. For example, language is abstract and can be absolutely meaningless without real associations. How many times have we been mislead into thinking that a child knows what he is talking about because his descriptive picture seems so complete? I went to the home of a totally blind boy who happened to be extremely verbal in spite of being very sheltered "because he might get hurt". The child was eager to share the fact that they had gotten a kitten, and proceeded to describe it in detail, and telling me that it was his job to feed it. I was thrilled for him. When I asked where it was, the father told me that it was outside and they wouldn't let it in because cats carried germs. In fact, the child had never touched it and his sole "active" involvement was putting a bowl of food on the floor and calling the kitty to dinner. The child knew how to repeat descriptions he had heard, but had no real idea of what he was saying. He wouldn't recognize a kitty. With sadness I listened to more empty conversation from the boy and carefully waged an effort to convince the parents that experiential deprivation would be more detrimental to the child than "dirt".

On another occasion, a child came home from preschool and excitedly told his mother that they had "made a cake." When asked how they did it, the reply was "Oh, ya just move a spoon around in a bowl." Because that was the only part of the experience that he actively participated in, it was his only concrete perception of what was involved. Obviously his sighted peers had a more complete picture of the total process, even if their only active involvement was stirring too. Fortunately, the mother picked up on this and the child shared in making a cake at home, experiencing all the steps.

Even with a good experiential foundation, I am aware of sophisticated thought processes needed to "visualize" what is happening when only words are the clue. Once I spent the day with a family and their 9-year old totally blind daughter. We developed car trouble. The first clue was the smell of gas. On checking, someone observed, "Oh, look, there must be a leak in the fuel pump. See the drip?" Later, the child made the comment, "A leak is a drip." She had been working on trying to understand what was happening and "leak" and "drip" were the only concrete aspects of the conversation, from her perspective, for which she had any associative foundation. There was no way that she could comprehend the total situation, any more than I can understand what makes my car work. However, we did talk about "leaks" to help give her more information for association. We discussed that

leaks can be drips, but they can also be air, such as when you let air leak out of a balloon; and that if the toothpaste leaks out of the tube, it doesn't necessarily "drip". In effect, we tried to give her tangible examples to demonstrate what was being described as a leak. What was interesting was that she, in turn, exercised her mind (and ours) by extending the list of examples.

Another interpretation of EXPERIENCE that is vital is practice. Too frequently we "help" the blind child who is capable of doing something, to save time or frustration. In effect, we are hampering that child because he is not getting the practice that will help him to smooth his skills. Practice is what leads to proficiency. We often overlook the fact that a sighted child sees others performing tasks, picking up visual clues for efficiency, without actually going through the process. The only way that the blind child will get the necessary reinforcement is by actively repeating the experience and its variations. During any shared activity, we should continue to ask, "Am I doing things that the child could actually be doing?"

In addition, interest and purpose will enhance practicing. If, for example, a child is learning to sort coins in school, has he had the opportunity to understand how he can apply the skill? Has he been able to go to the store or cafeteria and used coins for exchange? There needs to be a concrete foundation based on active, logical and sequential experiences, with enough reinforcement and variation for generalized application.

EXPECTATIONS:

In the past, I have capsulized the "Sequence of Doing" into AWARE, CAN, HOW and DO (with motivation.) In effect, IF the individual was aware of things out there to do; knew that it was within his capabilities; and learned how, then it would happen. That was putting a lot of weight on EXPOSURE and EXPERIENCE, and not enough emphasis on success's contributing factor of EXPECTATION.

The reality is that application of information is highly influenced by the expectations of others. The blind child has less of an opportunity to be influenced by peers and role models for self-initiated challenges, and responds to what he perceives to be the expectations of others. What has been observed to be inconsistencies in a blind child's behavior may in fact be inconsistencies in the expectations of others. For example, on occasion I have observed a child demonstrate a higher level of self-help skills and

independence in the school than at home. Conversely, there have been times that the school personnel was unaware that a child was doing something at home because they didn't see it happen at school. Communication and teamwork is essential, not only to understand the child's foundation and capabilities, but also to coordinate the process by which the child understands what is expected.

Learned helplessness can take over because others are uninformed as to what to expect with blindness. It can also be a reflection of pity, which the child can pick up. I had the good fortune of seeing the "pity hypothesis" challenged by a 4 1/2-year old who had lost vision at age 3. His father had asked him to feed the dog, and he complained, "I can't, cuz I'm blind and it takes too long." The father retorted, "Son, you may have lost your vision, but you did not lose your ability to do your chores like the rest of us." A huge grin crossed the child's face as he left to comply.

Behaviors may also reflect conditioned responses rather than potential. In walking, for example, one child in particular pulled back, and let whoever had hold of her hand take charge. Yet, if her hands were full and other modes of mobility guidance had to be used, such as a light touch on her shoulder, she would be erect and move much more freely. It was as though she thought you "expected" her to be dependent when you took her hand. Another child was resistant to intervention that introduced her to new things. She got into a pattern of complaining and needing to be coaxed to cooperate. This not only prolonged the activity to and produced frustration, it also denied others the opportunity of seeing how quickly she could actually comprehend what was wanted. During a cookie-making session that incorporated all sorts of concepts in a fun way, the child resisted the "goo"--dropped batter deliberately--and complained incessently. After assessing that the task was not too difficult, I finally sternly commented that, "I don't let my own children act that way and I don't expect <u>you</u> to." She paused, processed, and almost immediately started working quickly and accurately, shocking me into wondering how many other things she was capable of, but not yet demonstrating. Plus, we ended up having shared fun!

<u>ENJOYMENT:</u>

Although active EXPOSURE, EXPERIENCE and EXPECTATIONS are necessary contributors to success for the blind child, I am finding that ENJOYMENT is also a powerful component. I once heard the statement that "Nothing purposeless perpetuates itself," and it gave me much food for thought. The goal is

maximum independence, but for the blind child--what is the motivation? The ENJOYMENT factor has a strong influence on self-initiation. It takes lots more work and energy to learn about things and get to the point of being able to do even the basic survival skills with ease, when there is severe visual impairment. But, as I look closely at the children who seem to be a bit freer...a bit more involved in life...the "Doers," I also see a common thread of enjoyment. Think of the role that it plays in all of these areas:

Exposure: When the parents begin to really enjoy their child, it is an indication that they have started to deal with their feelings about blindness and are beginning to understand and accept their child as he is. From the child's perspective, it seems to add essence to his life. From the parents' perspective, when this occurs, there seems to be more inclination and energy to share, rather than withdraw from situations. The quantity and quality of exposure is enhanced.

Experience: If the child is enjoying an experience, it reflects that he is comfortable. Maximum energy is being directed towards the experience itself, rather than being lost to focusing on ways to resist, or in assessing what is wanted or even if the situation is safe.

Expectations: When enjoyment is expressed in meeting expectations, it indicates that the success/failure ratio is realistic, and that the child has a REAL opportunity to EARN self-esteem. The message, from the child's perspective is I CAN DO IT!

This would be the ideal place to say "That's it!" However, others have pointed out that I would be remiss if I didn't at least touch on some of the other things to be considered concerning blindness and I CAN DO IT, SUCH AS:

ESSENTIALS: Each individuals situation should be adequately assessed with regard to aids, equipment and skills that would promote independence. Would braille or large print be most efficient? Can low-vision aids make a difference? Has equipment been provided? Has a skilled Orientation and Mobility instructor been involved? Have all resources been made available?

EFFICIENCY: Even with the best of tools, the results will not be maximal if the individual has not been taught the most efficient techniques of their use. There are thousands of low-vision aids that remain in drawers because introduction of the use was limited to the doctor's office. Too many people have given up braille out of frustration because they were not taught (or did not practice enough) in a way that would reduce "scrubbing" and back-tracking. Many people sit home because they have not mastered independent cane travel. In effect, lack of efficiency is the inhibitor.

ENERGY/EXHAUSTION; It takes more time and energy to process tactually and auditorily, without instant integration of the whole, by use of vision. Therefore, we must be aware of salient fatigue factors. A 5-year old totally blind child, for example, was put in a chaotic class with 25 other children. Although she was able to do the work, her mother recognized that she was coming home absolutely exhausted. Trying to sift through the ambient sounds in addition to understanding the other things that were expected took lots of energy. Moving her to a quieter class proved less stressful and more productive.

EXPLANATIONS; The blind child deserves to have things explained. One time a teacher complained that the blind child in her regular class did things to get attention. In assessing the situation, it was observed that the teacher told the children to get their books ready. The blind child had a desk with a shelf below and slipped the book out. He then took it and slammed it loudly on his desk at least twice. The teacher demonstrated agitation. At the same time, she seemed to be totally unaware of the fact that the other children had taken their books out of their lift-top desks and were letting the tops bang down. It turned out that the blind child had no idea that the desks were different and in his effort to be like the others, he tried replicate the noise that he heard them make.

ESTEEM; Self-esteem cannot be given. It must be earned. Yet, too often false praise is given to a child because of his blindness rather than because he earned it. One time a teacher was overheard repeating "nice walking" to a 3-year old total who had been able to walk for a long time. She thought it would make him "feel good". Actually, the real message that he was getting, since the other kids that were doing the same natural thing and didn't get similar praise, was..."Nice walking...for a blind kid." It has even been found that many people

continue to talk to their blind child much longer in the tone that they talk to babies.

Expectations often differ and the child is deprived of the opportunity to really test his potential. One year a child had a teacher who would accept his work even if it wasn't complete. After awhile, classmates began to resent this unnecessary favoritism, but the child was unaware of the feelings. It wasn't until he had a more demanding teacher and experienced detention with others who were late with their work, that he really felt that he belonged.

EXTRA-CURRICULAR INTERESTS; Isolation can be a real problem. The blind child deserves the opportunity to develop interests that will give him an identity beyond blindness. People like to be around others who are interesting and fun. With so much one-on-one necessary for initial learning experiences, it is easy for a blind child to become self-centered. Extra curricular activities will help get the child involved with others.

ENCOURAGEMENT; It must be kept in mind that vision plays a strong role in encouraging continued efforts. Simple glances can send the message that the child is on the right track or is pleasing someone. Also, a quick visual scan can give the information that a task is almost done, or that time is almost up. The blind child needs tangible ways of processing the same information. Additional positive strokes and verbal comments are fair. Helping the child to identify non-visual ways of assessing time components or introducing the steps of a project also helps.

EXCUSES; There are times when it is appropriate to use the eye condition as an exception for special treatment. The child should learn how to describe his needs comfortably, such as sitting in the front of the room to take advantage of any useable vision.

Unfortunately, there are lots of inappropriate behaviors that are allowed to perpetuate with the excuse of blindness. The child misses the visual clues that others may not also do what he is doing, such as flicking his hands, or rocking, and that it is drawing attention to him. He does not receive subtle clues that his actions bother others. People worry that they will make the blind child self-conscious if they bring it to his attention. But, the child deserves to know that he is distracting and how, before people avoid him due to THEIR discomfort.

EVALUATION; Although I believe that it is unfair to compare a blind child with one who can see, I do feel that it is good to take an occasional look at what other children at the same age are doing. This may allow a more realistic picture. If there are concern areas, you can ask, "Is it the blindness that we are dealing with, or something else...like the fact that the child is becoming a teenager?" If there is a problem related to the blindness, then take time to evaluate and address the total dynamics.

IN CONCLUSION: I have ended up using enough "E's" to rival the number of E's on an Eye Chart in the Doctor's Office! But--it is just a start. There is still the rest of the alphabet...and, WE CAN DO IT!

PERSONAL IMAGERY AND THE VISUALLY HANDICAPPED

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The purpose of this paper is to share some information and interpretations gathered during many years of observing blind persons and their work in visual art.

The first involvement was in 1973/74 with children at the Jericho Hill School for the Blind operated by the Province of British Columbia.

A program was planned at the suggestion of the physiotherapist, Mrs. Elizabeth Wilmot, who felt that certain art activities would have broad beneficial effects on the children attending the school.

As a result of the planning and with the cooperation of the school administrator, a weekly art activity was implemented. Two groups of blind children ranging in age from six to eight met in the morning, one group before recess and the other after.

The activities carried out were mostly clay modelling but included work with many other materials. Pliable materials such as textiles, plastics; rigid materials, such as card, wood; nature materials such as flowers, evergreen branches, pebbles and shells.

Most activities were individual in nature but several large room filling constructions made from unfolded corrugated card board boxes required cooperation and group work. Some time also was devoted to making simple musical instruments and sound makers.

Black and white photographs, colored 35mm transparencies and video tapes were used to record the objects and activities.

From the sessions we observed. Also certain changes in the children's behavior. Some of the changes were not necessarily the result of the art classes alone, but from our discussions and evaluations of the sessions during recess break and noon, we observed these characteristics:

1. A growth in the skills of self expression which is clearly recorded in the photographs of the children's work. The development is most obvious in their clay work.

2. A marked growth in their stamina and ability to persist at an activity.

3. A continuing reluctance on their part to attempt new material or a new activity.

4. A persistent muscular weakness and poor strength in their hands when it came to manipulating clay.

5. An increased awareness of and ability to render three dimensional qualities, again especially evident in clay work.

6. An interesting change in their verbalized fantasies. Most children began the year with a repetitive and very personal set of fantasies which formed the subject of their clay productions. One child always talked about hospitals, transfusions, messes, etc., etc.; another talked of a mother-home-cat situation; and another always created things to eat. What gradually appeared to happen was that these personal and repetitive fantasies gave way under class motivations to imaginative expressions which were much more varied and related to the child's current or recent experiences. In short the art sessions seemed to take the children outside of their repetitive preoccupation and make them relate to current reality which we felt was a significant advance.

7. There developed amongst the pupils a marked inclination to share their own creations and to appreciate another's work without any sense of competition. The children really enjoyed each other's efforts.

8. There was a great delight and considerable value in the socializing that went on as they worked together. Most of the talk was about their work, and advice and comments were freely exchanged.

At the end of the school year, the program was judged successful by the school administration and consequently was repeated in the following school year.

From the record of the childrens' work done over these two years, it was clear that the visually impaired children displayed many of the same qualities in their work as were evident in the work of sighted children. There was

confidence in attacking large themes eg. a rock band concert. Many works showed the characteristics which make childrens' art work so impressive; exaggeration of certain parts of a form, elimination of non essential parts of an image, creative and imaginative subject choice.

As a result of these two years of experience and because of a curiosity to see what other schools for the blind might be doing in art activities, the author applied for and received in 1976 a Canada Council grant. The award was used in 1976/77 to travel and observe the art programs in twelve schools for the visually impaired throughout Canada and the United States.

From the evidence gathered a report was submitted to the Canada Council. As a result of the survey the conclusion was that there were very few instances where art/craft activities were being used as an avenue for personal expression. (Macdonald, 1978).

The experiences gathered from observing the types of art/craft programs in the schools visited reemphasized the need to plan programs to encourage the visually impaired to use their imaginative and expressive abilities.

That the visually impaired have at least equal if not superior imaginative powers in the belief of Johnson (1979) "Whatever the reason for the apparent superior creative imagery of blind adolescents, it is clear that every opportunity to promote imaginative thinking should be utilized, particularly in the areas of reading, creative writing, dramatics, music and art."

After 1978, efforts to continue working with blind children were made difficult when the B.C. Government "mainstreamed" blind students. As a result it was impossible to find a large enought group with which to continue the art activities. Eventually a group of three students was available in a Vancouver elementary school. With the cooperation of the principal and the students' teacher, a weekly all-afternoon art session was organized.

The ages of the students were from eight to eleven and one of them had been in attendance at the previously described Jericho classes. The activities carried out and the results were much the same as those already described in the Jericho project. The art classes at this school were carried on for two years and all the work by the students was photographically recorded.

In 1980/81 a program of a slightly different nature for the visually impaired was planned with the assistance of Christopher Cooke, a doctoral student in the Department of Special Education at the University of British Columbia. This program was titled "Art Activity and Physical Activity Related to Self -Concept Amongst the Visually Impaired."

The hypothesis was that by experiencing carefully chosen physical activities of a non-competitive nature the participants would gain in concept and perception of: spatial relationships, body image, size and scale; and relationship of limbs on the human figure. It was planned that this increased awareness would be reinforced by being translated in clay modelling. The art sessions were meant to yield a three dimensional version of their recently attempted physical activity.

The meetings took place at a Vancouver secondary school. The first hour of each session was devoted to physical exercises and the second hour to the modelling of one or more of the exercises attempted. The sessions were two hours, one night a week from January to April. Because of the transportation difficulties there were only two students who regularily attended. The results of the clay work were again recorded photographically.

The clay images produced in this program did not have the highly imaginative quality of the work done in previous years' projects. The reason was that in these sessions the subject for modelling was prescribed and not left to personal choice. However another facet of the art work of the visually impaired became evident and was made even more obvious in the following years' project.

In 1981/82 a grant was obtained from the Provincial Government in recognition of the International Year of Disabled Persons. The grant was to carry out a program similiar to that of the previous year, combining physical and art activities. With the cooperation of the CNIB who helped us contact participants and offered us the use of suitable space in their Vancouver building, we gathered together six persons and held ten, two hour sessions. The participants, two females, four males, ranged in age from 15 to 35 years. Two had some sight but were legally blind.

The session started with an hour of physical exercises consisting of many Yoga type movements. On most occasions a human skeleton was available for discussion about proportions of limbs, main bone structures and articulation of joints.

The instruction in modelling techniques had been given at the beginning of the project and was confined to teaching the participants how to work with clay in order that their productions would survive the drying and firing processes. Again the results were photographed in black and white and colored transparencies. Also a short video tape was made from extensive video taping carried out by students from the Faculty of Education, University of British Columbia.

As in the previous years' clay pieces, there was not evident the imaginative and creative qualities noted in former programs. The subject was prescribed more or less, and although the participant chose the exercises to portray, the image was always of figures. However, another artistic quality became evident and that was that each participant had a personal style (image) in their work. This personal way of treating form persisted and was more obvious as the work accumulated over the months.

From the years of work with children of primary school level, young adults and adults, several facts became clear:

1. The visually impaired can be as expressive and creative in certain visual art activities as the sighted.

2. Their growth in visual imagery appears to pass through the same stages as the sighted person's.

3. The expression of experiences is no less brilliant and original than that of the sighted person.

4. The fact that a visual art "style" becomes evident in the work of older participants parallels the difference in child art and adult art of the sighted.

The evidence that this style or personal imagery persists in spite of lack of sight is an intriguing thought. Clearly "Imagery is a private experience whose formation is not necessarily dependent on vision, its occurence may be the result of input from other senses as well as recall". (Khatena,, 1983).

The implications of these experiences with the visually impaired and their visual art seem clear. The work done by the blind is as imaginative and stylistically consistent as work by the sighted. These conclusions arrived at empirically are supported in some facets by the publications of Johnson (1979 and 1980). Therefore it is essential that the visually impaired be allowed to maintain their undiminished imaginative abilities and that suitable visual art activities be offered to all ages and conditions of the blind population.

That the blind can produce works of art is attested to by the writings of Fukurai (1969) and Lisenco (1971), but producing fine art is not necessarily the main value in art activities for the visually impaired.

For anyone to understand themselves and their environment, many of the modes of organization are achieved through non-verbal means of experiencing and expressing. Sir Herbert Read has said: "One of the most curious fallacies of the modern age has been the assumption that a limited series of signs - namely, words arranged in an order called logical is sufficient to communicate not only all factual knowledge, but also the nature of all sensations, the quality of all emotions, and the content of all intuitions."

We owe it to the visually impaired to ensure that they have the opportunities for a balanced physical and mental life that we all should enjoy.

REFERENCES:

Fukurai, Shiro. How Can I Make What I Cannot See? New York; Van Nostrand Reinhold, 1974.

Johnson, Roger A. Creative imagery in blind and sighted adolescents Journal of Mental Imagery, 1979. 3, 23-30.

Johnson, Roger A. Sensory images in the absence of sight: blind versus sighted adolescents. Perceptual and Motor Skills, 1980. 51, 177-178.

Khatena, Joe. Mississippi State University, Department of Educational Physchology, letter to author December 1983.

Lisenco, Yasha. Art Not by Eye, New York: American Foundation for the Blind. 1972.

Macdonald, J.A.S. Personal imagery and the visually handicapped, Visual Impairment and Blindness, 1978. 72, (5), 184-186.

LIVING SKILLS
THE DUAL ROLE OF THE PARENT AND THE PROFESSIONAL

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The topic of teaching skills of daily living to the visually impaired child is extremely broad. I plan to approach it stressing three major points. Firstly, the process of teaching skills of daily living must begin as early as infancy and must not be viewed as an entity unto itself, but rather as a part of a whole learning sequence of experiences and general skill development in all areas including mobility, recreation, social skills, and academic learning. Secondly, the parents have an important role to play in this process, in order for the child to achieve his maximum learning potential. Thirdly, the professional should primarily be a consultant to family members and those persons close to the child and his family (particularly in the preschool years), rather than taking over the whole job of teaching himself. If parents and professionals can work together in this way from the start, a solid learning base for skill development is possible.

I am especially interested in integrating the roles of the parent and professional since I have been working professionally with visually impaired children and adults for several years, but also have been blind since birth and have experienced many of the frustrations I see in my students when they are learning a skill. In retrospect, I realize the tremendous help and encouragement my own family gave me as I was growing up and without this support I could not have gained the success and independence I enjoy today.

First of all, one must distinguish between the problems of the congenitally and adventitiously blind person. For the past several years, I have been teaching rehabilitation in a ten-week Adjustment to Blindness program. Our students are mainly young and middle-aged blind or partially sighted adults, who receive instruction in four core areas -- mobility, braille, typing and skills of daily living. Other areas such as recreation, sensory awareness, crafts, counselling, group therapy, and social skills are also included. My experience in working with both congenitally and adventitiously blind persons seems to shown that, generally, both groups have difficulty dealing with feelings of lack of self-worth. However, there are some important differences.

For the person who has recently lost his sight, one of the main stumbling blocks is overcoming his own fear of blindness and regaining the confidence that he can, for the most part, resume his normal familiar routine. For him, this confidence is regained by his learning new adaptive techniques to perform old familiar tasks; and it is this security and reliance on previous experience, coupled with being expected to fit back into his previous life-style, that automatically integrates the new skills into his routine. Because it is a return to a familiar environment, this is pretty much an unconscious process, with the exception of learning entirely new techniques such as typing and braille. His biggest frustration now is that he does not seem to get quite as much accomplished in the same length of time as he used to, because everything just takes that little extra time.

By contrast, the congenitally blind persons we work with generally come to us with limited life experiences and these experiences have been very selective and do not cross-reference with each other. Their present home environment is very sheltered and they have had to do little for themselves. Any skills of daily living they learned at home or in school are often perceived as exercises like math or reading to be done for fun or if they feel like it. This probably stems from the fact that they were never really expected to continue to use a skill on an ongoing basis, once they had learned it. It only needed to be filed away. It is not an integrated part of a daily routine. The question is, how do we avoid this compartmentalized approach to the learning of skills?

To begin this discussion of integrating the skill areas into a composite whole for the blind or visually impaired child, let us talk about sensory development, both in terms of isolating individual senses, and also in terms of thinking of these senses as a full set of tools, without which the child cannot gather complete and accurate information about the world around him. Because the senses of hearing, smelling, tasting, and feeling are more limiting than sight in most respects, it is important for a blind child not to become limited in the way he views himself and his world. Poor use of important sensory clues results in confusion and a lot of misinformation. If he is not able to make sense of the sensory clues he receives, often he relies on an overactive imagination to explain away the confusion. This constant turning inward for clues about his environment can be very isolating for the child, though he may be totally unaware of it, and can result in a very poor understanding of his environment.

As part of the sensory awareness component of our Adjustment to Blindness program, our students are asked to listen to and identify common everyday sounds. In the beginning, I made the assumption that congenitally blind students would do much better than those who had more recently lost their sight, since they were more familiar with sorting out auditory information. I was surprised to find that this was not the case. In most instances, the explanations given by congenitally blind students were totally unrelated to the sounds they heard. A simple game of shuffle-board, for example, became a long and involved story of several people arguing over whether or not to go to a movie. The student focussed on the voices without hearing what was said. Other important clues such as the fact that the game players were discussing scores, or the sound of the rocks sliding and hitting each other on the board, were totally missed. Since the voices meant nothing out of context, because the student had not paid attention to what was being said, the whole listening experience meant nothing, and so, he invented a story to make sense of it.

As earlier stated, both parents and professionals have important roles to play in integrating a blind child's learning experiences. Because a parent can spend more time with the child than the most dedicated professional can, he is in the best position to have a direct and consistent influence on the way the child perceives the world. Therefore the following suggestions are ostensibly directed to the parent. However, because the roles of parent and professional are so closely related, these suggestions are of interest to both.

If the child cannot see, there is all the more reason to talk to him about the things others see, even abstracts like colour. This does not mean that the child will understand what a particular colour looks like, but he should realize that everything in his environment has colour, that certain colours are considered to "match" while others do not, that there are feelings and emotions connected with colours, that the majority of the rest of the world considers colours very important, and that blind persons should be aware of the colour of their clothes and other personal articles (for identification purposes if for no other reason).

How does one develop an appreciation of colour in someone who cannot see it for himself? In describing a new article of clothing, include colour in the description. Talk about other pieces of clothing in the child's wardrobe that can be worn with the new item. When you decorate his room, or for that matter, anywhere else in your house, talk about the colour scheme, the pictures on the walls, the furniture and any other distinguishing features that give the room character or uniqueness. Don't leave out things just because he cannot see them.

When we were first married and picking out furniture for our new apartment, my husband and I were both surprised to find that I had very definite ideas about the colours I wanted around me, even though I could not, and never had been, able to see them. I wanted warm rusts and browns and he preferred blues and greens. Where did I get these ideas and feelings about colours? From hearing other people talking about colours and people feeling it was important to talk to me about them.

When I was in high school, it was compulsory for me to take Grade 8 Art. It proved very useful. Much of the course was art history and theory -- the primary and secondary colours, colours in the spectrum, understanding perspective in drawing, etc. The experience did not improve my drawing, but I did have a better general knowledge of the subject of colour.

When I graduated from high school, I moved away from my small home town and moved to Penticton to take two years of private singing lessons. Because my singing teacher was interested in my perceptions of colour, we spent some time discussing it. He explained colours to me by using the technical terms he used to teach singing and also related them to the emotional qualities and sounds of music itself. It was a rather abstract explanation but it added another dimension to my colour awareness.

What does all of this have to do with skills of daily living? Being able to process information accurately, quickly and completely is one of the biggest assets in learning any skill, and also it enhances the child's ability to use that skill effectively. How does one develop the discriminatory ability in a visually impaired child? Start early, and be consistent in your approach. For example, from the time your child is an infant, talk to him about the ironing, the washing, the cooking, the dishes you are doing, even though he is not able to participate in the activity. He will begin to unconsciously relate the sounds he hears with the act that is being done and this will help to make what he hears relate to concrete things in his world. If it becomes a habit for you early, it will be easy for you to continue and extend the process, once the child can actively participate in a particular activity.

When you are shopping, not only take the child with you, but make the experience more than simply a passive one for him. Show him the carton of milk you just bought; comment on how cold it is in the frozen foods section; draw attention to the smell of the onions and the colour of the tomatoes in the vegetable department.

I grew up in a small town where there were only two main clothing stores. When I received clothes for presents, I could tell from which store they were purchased by their smell. This in itself is not a particularly useful talent, but it showed that I was beginning to discriminate and use subtle clues to gather information about my environment, making judgments using this knowledge, rather than simply concocting a story to explain it or paying no attention at all. This discriminatory ability was not so much a result of specific lessons isolated from context as much as it was a result of my simply being encouraged to have many and varied experiences, and of my parents' chatting with me about my environment as I interacted with it.

The next step is for the child to put this discriminatory ability to practical use and make it work to his advantage. Begin by asking him leading questions. Start with something like, "Do you smell that nice leather?" as you are buying new shoes. The next time you pass the shoe store you might ask, "What is that nice smell?" The next logical step is for him to begin asking the questions of you. This process will not only help him sift and sort through the jumble of information he receives constantly, but developing a sense of inquisitiveness will stimulate him to transfer this ability to all skill areas and experiences, so he gains more benefit from them.

When a blind adult sets up housekeeping for the first time, he often finds that he needs a labelling system in order to function. Parents do not always realize that blind children also need a system of identifying common items in their home. Parents can easily supply the information that would otherwise be gained from such a system; however, this not only fails to take account of the child's need to identify objects in his environment, but more generally fails to encourage the sort of hands-on experience I have been discussing. Many labelling systems are possible. The important thing is to choose the one most appropriate for the particular item. For instance, appliance dials may be marked with bits of tape, tactile glue, or nail polish, either coloured or clear; canned goods may be marked with braille or large print dymo tape stuck to magnetic tape; two identically packaged items may be distinguished by using elastic bands or safety pins. However, one can have too many labels and become obsessive about the whole process. Many things in the kitchen can be identified by type and shape of package, weight, texture, smell, sound when shaken, or, except for poisons, which are generally kept in a separate cupboard, taste. I often work with a group of students taking random foods from the cupboard and refrigerator, and having them identify each one using the criteria just mentioned.

They are generally surprised by the number they can guess correctly, once they know what distinguishes one from another. For the younger blind child, such an exercise could be made into a game, for this is part of learning how to integrate his senses.

One aspect of teaching that I have only indirectly mentioned is the necessity for the visually impaired child to understand basic concepts. Since this subject has been dealt with more than adequately in many conferences, articles, and books discussing visually impaired children, my intent is simply to discuss some of the assumptions that may show up as difficult stumbling blocks to teaching for both parents and professionals. Certain concepts that are obvious to us, and that we accept almost unconsciously, may be lacking or misunderstood by the child. Oftentimes, these gaps become apparent when one simply talks to a child, but this is not always reliable since children can often verbalize things they do not in reality understand. When I was preschool age, I used to call constantly to my mother, who was working in the kitchen, to look at something I was doing in my bedroom. After many such interruptions, she finally told me she was busy and couldn't come to look. After puzzling over this for a while, I responded that she didn't have to "come," I just wanted her to "look". This prompted an explanation of how, though it is quite possible to hear around a corner, sight does not bend that way. On another occasion, I remember confiding in my grandmother that I was very concerned that when I was grown up like her, I wouldn't be able to reach the top of my head to comb my hair, because my arms wouldn't be long enough to reach that high. Another discussion followed.

It isn't quite so funny and much more serious when such misconceptions persist into adulthood. When we had a problem with one of the toilets in our CNIB service center, we discovered that one of our students -- a man in his thirties -- was consistently using too much toilet paper for the drain. He seemed totally mystified when we tactfully approached him about this. He only understood the problem when we demonstrated the expansion properties of toilet paper by placing a small amount of it in a bowl of water. The final component of the experiment was to compare the expanding paper with the size of the toilet drain. Our plumbing problems ended.

Toilets seem to present interesting and varied problems for blind children. I have seen two extremes. There was a child who spent endless hours flushing the toilet, because he was fascinated by the sound it made. I, on the other hand, was very apprehensive about flushing toilets, because I feared I

might be sucked down the drain. There was a child who refused to use the washroom on a train because the noise of the wheels on the tracks sounded so clear when she was using the toilet that she was certain she would fall through the hole. Obviously, long careful discussions were needed to dispel these very real fears. Both parents and professionals can greatly aid the teaching process by realizing that many seemingly unfounded fears a visually impaired child may have could be a result of gaps in his basic concept of how and why the world works the way it does.

From an awareness of the actual process that takes place, the next step is the hands-on experience of actually performing a task. Such experiences, in order to have meaning for the child, and be integrated with other experiences in his daily life, should ideally take place in the home, rather than be manufactured in a classroom setting. This theory is very nice, but there is one major problem that constantly recurs -- the time involved in teaching the skill, and the time it takes for the child to learn and integrate it. Both parents and professionals are faced with the same dilemma: there are just not enough hours in the day to fit everything in. It is unrealistic to expect a child to sort through the clothes in his closet to find something to wear, make his bed, fix his own breakfast, clear the table, do his dishes, and be ready to go out the door to school on time, unless he gets up at four in the morning. Sighted children are not generally expected to do all of these things for themselves, though, as a rule, they can work more quickly than their blind counterparts, and so can accomplish more in the same length of time. Unfortunately, not doing these chores can have many more far-reaching consequences for the blind child than it may for the sighted. The term "out of sight, out of mind" may be only too true for the former and this is why it is even more vital for him to take an active part in his daily routine -- he must learn what his limitations are and how he can work within them.

There are several solutions to this problem of time management. Dividing tasks into small but complete segments is helpful. It is not imperative that the child always start at the beginning of a job, because this could result in his never getting past the first two steps. The important thing is for him to understand the order of the steps involved.

When making a bed, for example, he might only be expected to place the pillow correctly at the top of the bed and pull the spread smoothly over it. As this becomes more familiar and can be accomplished more quickly, more steps to the operation can be added until he is making his bed entirely on his own.

Major learning tasks like putting on the sheets and blankets can be saved for days when there is more time, such as holidays and weekends.

Because bed linen is so large, in the beginning it is often hard for a child to understand its shape, since he cannot feel the entire sheet or blanket all at one time. One way to overcome this problem might be to use a model such as a crib or bassinet mattress, or a cushion roughly mattress shaped, for the bed. Use crib sheets, receiving blankets, tea towels, etc. for the linen. Using bottoms of sheets and blankets are good references to use in order to put them on correctly. Also, safety pins or sewn labels on the tops or bottoms can be used as distinguishing features.

A good indicator of a child's readiness for new learning tasks is his independence and success in doing familiar ones. Use these old stand-bys as a foundation on which to build new learning. Often the child himself will tell you when he is ready to move on, either by his being bored with the old job, or by his making a specific request for something new.

Take every opportunity to comment on how similar two totally unrelated tasks may be in terms of the skills required to complete them. Putting placemats straight on a square table uses techniques comparable to those required in placing pillows at the top of a bed. Setting an oven dial accurately using tactile labels on the stove, identifying packages, and measuring ingredients for cooking use the same skills as setting a washing machine dial using the same tactile labeling system, identifying the soap package, and measuring the soap for doing the laundry. If the child is constantly made aware of such similarities and differences between two jobs, he will automatically begin to make a transfer of skills from one job to another himself. The list of chores making up his daily routine will be seen as the learning of a few basic skills with which to work, rather than as a jumble of unrelated activities that must all be stuffed into a day. Developing this sense of a relationship between one job and another may also begin to teach him problem solving skills and he will be less tentative and more ready to attempt new and unfamiliar tasks on his own.

Although it is not always necessary for a child to completely finish an entire job, in order to increase his own sense of accomplishment and satisfaction, it is often an excellent idea to plan so that he is at least able to finish a particular section of it. But it is also very important that he realize just how much of the work he has done himself and how much help he has been given. Many of the congenitally blind people

we teach really believe they are able to do a great many more jobs than they actually can. When they are ultimately faced with the challenge of doing the job by themselves, they discover that much of the work was done by others, without them even being aware of it. To make this realization at age twenty-five or thirty can be very demoralizing and frustrating, and often is quite devastating to their motivation and confidence level when they are asked to tackle something else. They are overwhelmed by the startling discovery of just how much they thought they knew and how little they really do know. It is much easier for you, and more rewarding for the child, to receive praise for a job completed and done well than to be made aware of limitations, but always keep in mind the impact in later years of unrealistic successes now.

Thus far, I have been making specific suggestions as to how parents can help their children lay a basic groundwork of conceptual, sensory and experiencial development. What is the role of the professional in this process? There is no single answer to this question, because each child presents a unique case; one must take into consideration his home environment, the resourcefulness of his family members and the time they make available to him, whether he lives in a rural or urban setting and therefore what educational resources are available to draw upon, and the professional specialists around him. There is no defined split; the role is a dual one.

The biggest asset the professional can offer is his specialization and expertise in his field. One problem with this specialized approach is its possible tendency towards the compartmentalized learning perspective I have already mentioned. However there is another danger in this approach. The professional is often able to pinpoint specific problems the child is having. Such problems obviously need attention; however, if the professional simply intervenes to the extent of taking over a particular aspect of the child's teaching, the parents may interpret this intervention as meaning that they are incapable of doing the teaching themselves. This situation may be very devastating to their confidence level, and serve to reinforce the notion that teaching should be left strictly to teachers. Of course, in some cases, parents simply are not prepared to spend the necessary time learning how to teach their children; some parents of either blind or sighted children prefer to leave their children's education entirely up to the system. However, in the majority of children's learning, it seems to me tht the most vital part of a professional's role is to encourage them to work with their visually impaired child and give them confidence in their ability to do so.

This, of course, entails giving concrete support. Often, the professional can assist the most by providing suggestions for specific teaching techniques and strategems that parents could try in working with their child -- suggestions such as those outlined earlier in this paper.

The professional can also play a valuable diagnostic role, assuming he is sensitive in the way he applies the disgnosis. In many cases, children will perform for others, tasks that they claim they are unable to do for their parents. Thus a professional is in an excellent position to discover just how much the child really does know and then to encourage the parents to reinforce and continue the work that has been started. Beware of asking too many questions of both the child and the parents; often information given verbally is misleading -- test by doing. If the child is old enough, suggest cooking a simple meal; using convenience foods can be very helpful to save time and steps in preparation. If it is feasible, an outing can test and integrate both mobility and daily living skills. Once a list has been made, take the child shopping and see what you can find out from how he reacts to the experience. Does he pick up on sensory cues? Can he identify foods by their shape, texture, packaging, colour, smell, etc.? Does he have a sense of how much a particular item may cost? Can he identify denominations of paper and silver money, and is he able to pay for his purchase at the checkout counter? Obviously, steps can be added or omitted in this plan; it is only intended as a basic guide. The important process is to learn from the child and do as little actual teaching yourself as you can. I personally feel that this is the most accurate assessment tool you can use to test a child's basic skill level. Once you have gathered the basic information in this way, you are better equipped to suggest a program for him.

I reiterate: involve the parents as much as possible. Either do the majority of the actual teaching initially and then suggest that they do the ongoing reinforcement and follow-up, or provide them with some tips and suggestions to do the teaching themselves. Don't fall into the trap of feeling that, since you are the expert, you must provide the entire network of educational training and services for the visually impaired child and his family.

As a parent, fight as hard as you can against the feeling of being overwhelmed by having a child with a visual handicap. Concentrate on the similarities between your blind child and other children in the family or around him, rather than on the ways in which he differs from others. This does not mean the differences do not exist (one must always be aware of them),

but it does ensure that the whole situation is kept in some kind of positive perspective. Your greatest strength as a parent is that since you spend the most time with your child, you probably know him best and have intuitively discovered how best to teach him. Be confident and assertive enough to test it out.

When I compare how I would bring up a visually impaired child with how I am currently raising my own four-year-old fully sighted daughter, the greatest differences would be in the way in which I explained things to the blind child, and the greater emphasis I would place on hands-on, one-to-one activities. The experiences both children should have would be virtually the same.

In conclusion, I wish to emphasize that my main purpose in writing this paper has been to provide a completely practical approach to teaching skills of daily living to the visually impaired child. I have not tried to set forward any new teaching theories, but rather to draw together many of those that have already become well established. I have tried to focus on the necessity for the integration of all the skills a child must have in order to be an independent, self-reliant individual having confidence in his own abilities and feeling good about himself. If the child's learning is to be integrated rather than compartmentalized, parents and professionals must not compartmentalize their roles; rather, they must integrate them and share responsibility for every aspect of the child's learning.

SOME HANDY HOUSEHOLD TIPS AND TECHNIQUES

The following is a list of handy tips and techniques I have found useful either in my own home or in teaching blind students. These should be regarded as suggestions of ways to approach particular problems, rather than the only solution to them.

1. Labeling:

A. In general, do not be obsessed with labeling. Label only those things that cannot be distinguished by any other convenient means and keep labels as short and concise as possible.

B. Stoves, washing machines and other household appliances with dials can be marked with dots of "Hi Marks" special tactile glue or ordinary household glue, clear or coloured nail polish, or small bits of tape. Only mark essential numbers to avoid a cluttered dial.

C. Use large print or braille for marking spices, pill bottles, etc. When a particular item is finished, you simply transfer the new item to the old bottle, to avoid having to make new labels each time something is replaced. If the name can be shortened so that the label can be put on the lid of the bottle, you need only interchange lids.

D. Small plastic labels called "Plant Labels" can be marked in print and braille and attached to frozen food packages. They can be written with a brailler or slate. Frozen convenience foods, cake mixes etc. can be labeled with strips of plastic thermoform paper or file cards with the type of food and its directions for preparation and attached to the package with elastic bands. Clear plastic tops from boxes such as greeting card boxes may also be cut up to make labels.

E. Braille or large print can be marked on half-inch dymo tape and stuck to half-inch magnetic tape (usually available from hobby shops) for identifying canned goods. Can labels not in use can be stuck to the fridge or on a piece of sheet metal screwed to a convenient cupboard door. The storage space can be marked off in sections for each type of lable used. If tape of a colour other than black is used, labels can also be marked in print with a fine tip felt pen. This will facilitate sighted people helping to organize them.

F. To distinguish between a small number of identical containers, such as pop bottles, place different numbers of elastic bands around them. Alternatively, select brands so that no two items are in identical containers.

G. Clear plastic sheets called "Braillabel" can be used with a brailler or slate to make record and tape labels. These braille sheets can also be used for converting simple children's books into Twin Vision books.

2. <u>Organizing tips for laundry:</u>

A. Safety pins or Sock Tuckers can be used to keep socks in pairs for washing. It is helpful to buy socks of different colours with slightly different patterns or textures for sorting purposes. Small boxes can be used to divide drawers into sections for separating small items by colour.

B. If you count small items such as cloths, underwear and socks before putting them in the washer, you will be able to tell if some have been missed in the machine or dropped along the way when they are folded and put away. Also, washing small items in a pillow case or cheesecloth bag will keep them from getting lost.

C. Put a small safety pin in the label of one garment if you have two pieces of clothing that are identical except for the colour. Learn to look for differences in texture, style, type of buttons, collars, hems, etc. in order to distinguish one item from another. Small metal tags with colour codes brailled on them can be sewn into the collars of shirts or the waist bands of pants if colour co-ordinating is a problem. These are available from CNIB.

3. General organizing tips:

A. A recipe box with alphabetized index cards can be used for keeping phone numbers and addresses. The index cards can be labeled in braille and then individual phone numbers and addresses can be brailled on individual recipe cards and filed accordingly. Strange as it seems, it is more convenient for reading if the index tabs are labeled upside down on the back of the index cards; this allows you to hook your fingers over the index cards to read them. The address cards should be placed in the box upside down as well so they can be read without being removed.

B. A small shoe box or recipe box with labeled dividers is useful for keeping packaged gravy, sauce, salad dressing and other mixes. The dividers can include the directions for preparing a particular package.

4. Measuring:

A. Use measuring cups in graduated sizes rather than one cup with marked divisions.

B. Keep the bowl you are measuring into, close to the cup you are measuring from, to avoid carrying full cups across the kitchen. This will minimize cleaning spills on counters.

C. Keep liquids such as cooking oil and extracts in the refrigerator. The contrast between the coldness of the liquid and the warmth of your hands will make them easier to measure.

D. A large eye dropper can be used for measuring extracts.

E. If you want to add small amounts of salt and pepper or spices without measuring exactly, sprinkle them into your hand first so that you have some indication of how much you are using.

F. Medicines may be conveniently measured by using a "Pee Dee Dose," manufactured by Baxa and available in some pharmacies. This device looks like a large hypodermic syringe with no needle. Medicine is drawn into it when a plunger, which may be marked with notches, is withdrawn; the medicine may then be squirted into the mouth. It is particularly useful for administering medicine to children.

5. Pouring:

There are several techniques which you can try to see which works best. In general, start practising with cold liquids. A teapot, kettle, pitcher or any container with a narrow spout is probably the easiest to work with.

A. Place the cup or glass on the counter or in the sink. Hold the container of liquid to be poured in your right hand. (if you are left-handed, do the reverse.) Use your left hand to line up the pouring spout over the rim of the glass. Place the left index finger over the rim of the glass so that it is slightly bent down into the glass. This finger acts as a guide to ensure that the pouring spout remains positioned over the glass and also lets you know when the cup is full. Your natural reflexes keep you from being burned; when hot liquids touch the tip of your finger, you will automatically stop pouring and pull your finger back.

B. Place the cup or glass in the sink or hold it in your hand. Putting the cup in the sink makes messes easier to clean up and also the sink acts as a resonator. The sound of the liquid being poured changes as the cup gets fuller. If you are holding the cup in your hand, the changing weight of the cup as it is being filled is a good indicator of how full it is. If the liquid is very hot or very cold, this difference in temperature will transfer to the side of the cup as the liquid is poured into it.

C. There are various types of small battery operated devices called "liquid level indicators" which fit over the side of a cup or glass. When the liquid you are pouring reaches the two prongs of the liquid level indicator hanging inside the cup, it will beep, letting you know the cup is full. One major drawback with this device is that the batteries run out with no warning and the result may be a flood on the kitchen counter. Another problem is created if you rely solely on devices such as this, because you are stuck if you are out and have forgotten to bring them with you. However, they are very helpful for people who have neuropathy in their hands or fingers.

6. Spreading:

Initially, use toast instead of bread for spreading because you are less likely to make holes in it with the knife.

A. One technique is to place the bread on the counter or plate and spread it up-and-down overlapping strips from one side to the other. Follow the point of the knife with the index finger of your other hand to ensure that no parts are missed.

B. A slight variant to this technique is to place the spread in the centre of the bread and work from the centre outward in all directions until the surface is completely covered.

C. When spreading sticky substances such as jam, honey, peanut butter, etc., scoop them onto the bread with a teaspoon and then use the bowl of the spoon or a knife to spread them.

7. Peeling:

A potato peeler is usually easier to use than a paring knife. Start with carrots because of their shape. Peel in overlapping lengthwise strips and cut the ends off last. As you peel, run the vegetable under cold water from time to time. When the vegetable is wet, fingers will slide easily over the peeled portions and stick slightly to the places where the peel remains.

8. Cleaning:

A. To clean counters, start at one end and work to the other in long overlapping strips. This will ensure that no spots are missed and will leave you one pile of crumbs to dispose of when you are finished. Always use the hand not holding the cloth to check areas just cleaned for extra stubborn spots.

B. This basic method of working in overlapping strips works well for dusting and vacuuming and for washing floors, windows, etc. I find using an electric broom or vacuum is easier than using a broom or mop.

9. Some general hints:

A. Frying eggs:
Cut the top and bottom out of a tuna fish tin or other similar sized can to form a ring. Grease these rings and place them in a frying pan. Drop one egg into each greased ring. If you cover the rings with foil or a lid, you do not have to turn over the eggs. A flipper can be slid under the rings for easily removing the eggs from the pan.

B. General hints on frying:
When turning many pieces of meat in a frying pan, it is sometimes easier to place the pieces on a larger dinner plate and flip them individually and return them to the pan. This ensures that no pieces are missed in turning, and helps to prevent one piece of meat being flipped on top of another. I also have a flipper with a top that can be closed down over the meat, on the same principle as a pair of tongs. I often prefer oven baking or roasting meats, because they do not have to be turned over. This is particularly true of bacon, which is difficult to turn.

C. Testing meat for doneness:
Use a time guide and timer for approximate cooking times. Then do a finger test. Rare meat is softer, moister, and smoother to the touch than more well cooked meats. As meat cooks longer, it feels less moist, more firm, rougher textured, and sometimes crusty. Smaller amounts of meat are easier to work with if cooked in a toaster oven. When broiling, the smaller broiler is less unwieldy than a full-sized one and grease is less likely to spill.

D. Cutting meat:
When you are first learning to cut meat I would suggest practising with something square such as a piece of toast or plasticene or clay rolled out on a board. This way you can really feel what you are doing. A serated knife such as a steak knife is generally easiest to use. Hold the fork in one hand and stab the meat at the corner with the tines. Take the knife in the other hand and make a diagonal cut just behind the fork. Before lifting the knife, pull gently with the fork to see if you have completely cut through the piece of meat. If not, the knife is in a good position to make another cut. Each time you cut another piece of meat, start at a corner. With a steak, cut along the edge of the bone with the knife and remove it from the rest of your steak.

E. Gravy:
Skimming of the fat from meat drippings is difficult, even if the fat has risen to the top. If ice cubes are dropped into the dripping, the fat will congeal on the ice and the cubes can be removed.

F. Opening milk cartons:
Milk and juice cartons have two creases in the top at the end to be opened; these creases enable the flaps to fold back to make the spout. These creases can be felt, and if you pull the carton open at this end, it will be opened correctly.

G. An ice-cream scoop is useful for making muffins, cupcakes, etc. because it allows you to get equal amounts of batter in each section and is easier than pouring directly from a bowl or using a regular spoon.

COOKBOOKS AND CATALOGUES

The following is a short list of cookbooks and catalogues which you might find helpful. This list is by no means complete, but includes many of the books I use for teaching and for personal use. The majority of them are available in braille or large type. Check the CNIB Toronto Library, Crane Library, or contact the braille printing houses for more extensive lists.

AFB Catalogue: Aids and Appliances for the Blind and Visually Impaired:

American Foundation for the Blind (see address below). Available in print and braille.

International Guide to Aids and Appliances for Blind and Visually Impaired Persons:

American Foundation for the Blind.

Amana Radarange Microwave Oven Microwave Cooking Guide:

Amana Refreigerator, Inc., Amana, Iowa.

Beyond T.V. Dinners:

Canter, et al. Available in braille and large type from American Printing House for the Blind. (see address below).

Breads:

Marie Porter, Editor. Available in braille and large print from Guild for the Blind. (see address below).

Cook and Look Cookbook:

Ida Erickson, Biword Division of Maricom Corporation, Box 20, Willmar, Mn. 58201. Large type.

Cooking With Art:

Sue Hanson, Debora Stegora, Editors. Available in print with both instructor and student manuals from: Association of Rehabilitation Teachers, 4803 Monana Dr., Monona, Wisconsin 53716.

Cooking with Betty Crocker:

General Mills Inc., Minneapolis, Minniesota. Available in braille from: State Services for the Blind, 1754 University Ave., St. Paul, Minnesota 551404.

Cooking Without Looking:

Esther Knudson Tipps. Available in braille from American Printing House. (See address below).

A Leaf From Our Table:

Marie Porter, Editor. Available in braille from Guild for the Blind (see address below).

Pival Crock-pot Cookbook:

Marilyn Neill. Available in braille from: Beth Shalom Sisterhood Braille Committee, Mrs. Max Benjamin, Chairman, 8831 Esley Lane, Leawood, Kansas 66206. Available in large type from: Large Type Cookbook, 35 E. 107 St., Kansas City, Mo. 64114.

Preprimer Cooking:

Sally Jones. Available in braille and large type from American Printing House for the Blind.

ADDRESSES FOR SOURCE MATERIALS FOR SKILLS OF DAILY LIVING:

American Foundation for the Blind, 15 West 16 St., New York, New York 10011.

American Printing House for the Blind, Box 6085, Louisville, Kentucky 40206-0085.

Clovernook Printing House for the Blind, Cincinnati, Ohio 45231.

National Federation of the Blind, 218 Randolph Hotel Building, Des Moines, Iowa 60409.

Living Skills Center for the Visually Handicapped, 2444 Road 20, Apt. c - 205, San Pable, California, 94806.

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Lithographed in Canada by Broadway Printers, Vancouver